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AUTHOR Perske, Robert
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ABSTRACT

The book highlights 30 effective service programs for mentally retarded persons. The first section presents information on eight family oriented programs serving high risk, Down's syndrome, urban poor, and profoundly handicapped children. Included are descriptions of parent education, support, and advocacy programs. Among seven public school education programs summarized include a preschool program in which normal children are integrated, a merger between a special school and a regular one, a community centered program for hearing impaired retarded teenagers, and continuing education courses on college campuses. Among the five community residence programs represented are the Eastern Nebraska Community Office of Retardation, the Macomb-Oakland Regional Center (Michigan), and the Tuolumne County Independent Living Project (a rural California program). Three descriptions of effective vocational programs are followed by two self assertion projects. Two programs serving mentally retarded offenders and two serving mentally ill/mentally retarded persons are reviewed. Final sections touch on prevention and future issues (including consumer advocacy systems, special-regular teacher relationships, and local community responsibility). (CL)

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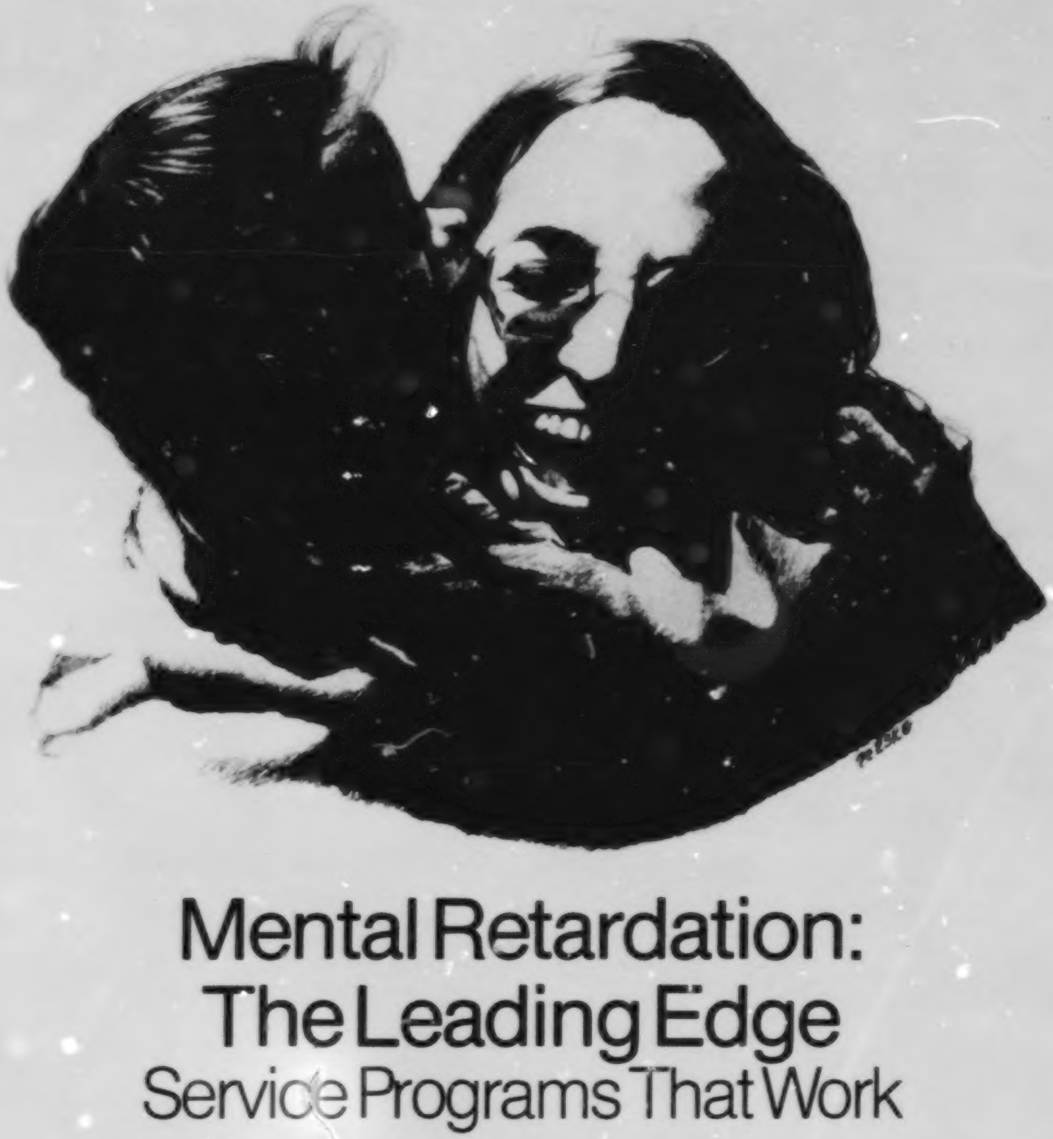
Report To The President



Mental Retardation: The Leading Edge

Service Programs That Work

PRESIDENT'S COMMITTEE ON MENTAL RETARDATION

EC121672

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ABOUT THE COVER:

Five-year-old Michelle could not walk when she was enrolled in a public school special education class in Hamden, Connecticut. But she showed remarkable determination when her teachers, her family and the workers at Camp Rainbow (a community-based service) joined forces and developed a program that might, someday, allow Michelle to stand up and move forward on her own. It wasn't easy; this mentally retarded child had to reach and pass many "milestones" that normal children take for granted. She had to learn to roll over, push up on her hands, crawl, sit up, and balance on her knees. Assisted by her team of helpers, Michelle worked on these detailed, sequential tasks for more than a year.

Then it happened. Michelle learned to stiffen her shaky legs and stand. And with her hands above her head, holding tight to the fingers of a helper, she moved forward. This qualified Michelle to be a candidate for the "50-Yard Walk" in the forthcoming Connecticut Special Olympics. It was at one of the practice sessions that Michelle "unhooked" from her helpers at the starting line and walked 50 yards unaided — for the first time in her life.

Paul Calaluce first recorded on film what happened when Michelle crossed the finish line that day as she and her teacher, Susan Mangen, hugged each other with an almost indescribable joy. Later, Martha Perske recreated the effort in another art form, in an attempt to show that such joy is part of the reward — for both the handicapped persons and their helpers — when milestones are reached in programs that work.

MR 78
Mental Retardation: The Leading Edge
Service Programs That Work

A Staff Report of the
President's Committee
On Mental Retardation

Washington, D.C. 20201

U. S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
OFFICE OF HUMAN DEVELOPMENT SERVICES
The President's Committee on Mental Retardation

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Robert Perske, *Author*
Martha Perske, *Artist*
Ian Elliot, *Editor*
Frank Golino, *Graphic Designer*
John DiGioia, *Graphic Designer*
Allen Menefee, *Project Officer*
Alfred Buchmueller, *Project Officer*

DEDICATION

This report is dedicated to Alfred D. Buchmueller, one of this project's officers, who died suddenly on Sunday, October 8, 1978. For seven years, "Buck" served with distinction as a staff member of the Committee, rising to the position of Deputy Executive Director. And in those years, he was always active on the leading edge of the mental retardation movement. This kind man worked overtime, inspiring and motivating others to utilize fresh innovations as they appeared on the national scene.

The influence of such a man as this does not stop when he dies. Buck's spirit will be with us for many years to come — as if he were still looking over our shoulders and cheering us on in our efforts to provide richer lives for citizens with mental retardation problems.

The Members, Staff and Consultants of the Committee

PRESIDENT'S COMMITTEE ON MENTAL RETARDATION
WASHINGTON, D.C. 20201

MAY 17 1979

The President
The White House
Washington, D.C. 20500

Dear Mr. President:

I am pleased to transmit to you a staff report which constitutes the Eleventh Annual Report of the President's Committee on Mental Retardation.

This staff report is entitled, Mental Retardation: The Leading Edge - Service Programs that Work. Rather than offering broad recommendations, it describes in detail a wide range of successful programs currently underway throughout the Nation. These programs share a common goal: to bring mentally retarded citizens out of a past of rejection and stigma -- into a future of hope, understanding, and personal pride as productive individuals.

The report shows that increasingly, mentally retarded persons and their families are working with representatives of business, industry, government, and community organizations in an effort to respond to the total range of programs associated with mental retardation -- from prevention to employment and independent living.

The Committee looks forward to continuing to work with you and Mrs. Carter.

Respectfully yours,

Joseph A. Califano, Jr.
Chairman

INTRODUCTION

Living in the present, we are prone to look to the past for the experience to guide us in shaping a new and more satisfying future. But the real hope of the future often lies in ventures which break out of the past and apply new tools to solve our problems.

Mental retardation is a human condition which has come with us out of a long and dismal past. The past of more than a few short years ago provided very little out of which a hopeful future for retarded people could be fashioned. Only as the leading edge of imagination and love has pierced the obscurities and misconceptions of past experience could the full possibilities of a good life for mentally retarded people be revealed and brought to fruition.

In recent years we have begun to develop new methods based on a new spirit of humane artistry in ameliorating the problems of mental retardation. We still have a long way to go; yet, as we look across this great land of ours, we find people on the leading edge of the present with new programs that work in providing satisfying and productive lives for people who are retarded — in family life, in the schools, in the places of residence, in work and in personal life. We find new relief of the spirit for retarded individuals and their families who grapple with inner agonies; new possibilities of constructive living for those in trouble with the laws of the community. We find a host of new approaches to mastering the risks of being born and the hazards of surviving intact in a difficult world.

This Staff Report of the President's Committee on Mental Retardation, to which Robert and Martha Perske made substantial contributions, highlights a few of the communities throughout the country which have service programs that are really effective with mentally retarded children and adults. It responds, in part, to Mrs. Rosalynn Carter's request for information on mental retardation programs that work. While this report focuses on effective service programs, it touches only briefly on another leading edge that is just as important: prevention. A full report on preventive efforts is projected in a future PCMR report.

Here then, are a few samples drawn from hundreds of equally exciting new ventures that are really working for mentally retarded people. The President's Committee is deeply grateful to all of the devoted workers in every part of the country who contributed freely and proudly a wealth of information on what they are doing from which these examples are selected. We know also that there are many more such programs in the making, not only on these designs but on other new and creative ones, as devoted people apply their minds and hearts to shaping the future for retarded people on the leading edge of our time.

Henry V. Cobb
Vice-Chairperson

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The Family

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A COORDINATED EFFORT TO TAKE THE RISK OUT OF "AT RISK"

An awesome package of forces comes as standard equipment with each newborn child. When the child is healthy and the environment is adequate, each intricately timed force triggers a portion of the rapidly unfolding natural process. Each organ is energized, enabling the infant to quickly triple in size, to become conscious of the surrounding world and to respond to it.

The most crucial period in the development of a human being is the first few years of life. For example, the brain begins a rapid development in the mother's uterus and continues until shortly after the second birthday. The process then slows down and never speeds up again.

We take these early automatic activities for granted in a normal infant, but this should never happen when there is the slightest suspicion that retardation is present. These "at risk" children need dramatic interventions. If ever there was a time when the helpers and the healers in a community need to come together on behalf of a family, it is when the unfolding forces in the baby of the family are being blocked.

Follow-up Intervention for Normal Development (FIND), San Bernardino, California

Every time a newborn infant in danger of being developmentally disabled leaves one of the area's intensive or intermediate care units, an elaborate case management system swings into action. A FIND counselor closely monitors the development of the child and coordinates the interventions of a large number of agencies throughout San Bernardino, Inyo, Mono and Riverside Counties. The counselor is trained and supported by the Inland Counties Regional Center, and the agencies which join forces are the County Health Departments, Public Health Nurses and Mental Health Services, as well as a number of public and private programs. "We have to work together to help these infants," says FIND's program manager. "These little people have not yet received a diagnosis of developmental disability and we are doing everything we can to see that they don't get one."

The process begins when a FIND counselor and key community agency representatives meet with hospital staff at the hospitals' intensive care discharge planning meetings. All infants found to be "at risk for developmental disabilities" (approximately 33 percent) and their parents receive specific follow-up interventions for 12 months after the child leaves the hospital. The FIND counselor comes to the home periodically to systematically assess and record the child's development, assist with the parenting process and see that the coordination of services is being carried out according to the individual program plan. The process has five vital targets:

- Do everything possible to increase the developmental levels of the infants.
- Do everything to stop secondary handicaps, even if developmental disability is finally diagnosed.
- Use every means available to assist with the development of parenting skills.
- Improve the utilization of all maternal/child health resources in the area.
- Collect vital data which can be used in realistic resource planning for the future.

Although there are many cases being coordinated simultaneously, each case has its own series of problems which must be skillfully examined and solved one by one. For example:

Richard, who had been flown to Loma Linda (CA) Medical Center shortly after birth, was treated for respiratory stress syndrome, sustained kidney damage, congenital heart failure and several infections. He was finally released to his parents at the age of three months. At that time, he was functioning developmentally at the one and one-half month level and was extremely irritable, with a negative reaction to touch by others. The FIND counselor coordinated an individual program that included assistance with nutritional management; advice on growth and development; help in healing the disrupted mother-infant "bonding" relationship caused by Richard's long hospitalization; assistance with referrals to Crippled Children's Services for funding, occupational and physical therapy evaluations; and emotional support to both parents, helping them to recover from their earlier harrowing experience of not knowing whether Richard would live or die. At the end of 12 months, Richard was functioning at the six-month level, and gaining.

Mary, a premature baby, was born in an ambulance on the way to the hospital. Her mother was mentally retarded and had received no prenatal care. When Mary and her mother were discharged five days later, FIND followed the "at risk" case closely. The mother, who had been living in an institution, was helped to move into a community residence. She received daily visits by a nursing consultant and a community worker who provided infant care training, mealtime scheduling and general assistance. Later, a live-in homemaker stayed in the residence when the mother began to neglect Mary—to the point where the baby's life was in jeopardy. Still later, arrangements were made for mother and baby to live in a family care home. Finally, when the mother became disinterested in caring for the baby, she was helped to put Mary up for adoption. Mary was adopted and at one year of age was "developmentally normal" and no longer "at risk."

The Family

This creative coordination of community resources has given rise to some significant developments. A few were unforeseen and came as happy surprises:

- Less than one-fourth of the infants on the caseload ultimately receive a diagnosis of developmental disability.
- No new services have had to be created. The program uses the efforts and resources of agencies that already exist.
- No additional funds are needed. The existing avenues of financial support are identified and used.
- This is one of the few programs in the nation that *does not* require a diagnosis or label before services can begin.
- Public relations efforts are not needed. All work together, quietly and efficiently, to meet the needs of the "at risk" children.
- A strengthening of family relationships and parenting skills is evident in almost all cases.
- There are no bureaucratic clashes and no rivalry for funds. Instead, all agencies share in the successes of the program. There is a

cooperative spirit at work, so that agencies offer support to one another when they attempt to justify their budget requests.

- In many cases, no medical care is involved. Instead, there are only preventative health care activities. Nevertheless, many physicians watch the processes with interest and support the interventions.
- The home, not the clinic, has become the arena for most of the interventions prescribed in the individual program plans.
- No child abuse has been found in any of the caseloads! Evidently, parents have been provided with enough supports and expressive outlets which diminish the urge to harm their child.
- The physician is no longer forced to make a hasty diagnosis. He can delay and watch the follow-up process until he is more certain about the presence or absence of developmental disability.

Although many of the results appear to be beyond the ordinary, those who collaborate on this program do not feel they are all that extraordinary. One FIND counselor, reflecting on the program, described its novelty this way:

> I don't feel we are introducing any new interventions. All of these specialties have been in the region for a long time . . . We don't seem to need a large bureaucracy to handle the coordination; we seem to get along very well without it . . . I guess you might say that the "at risk" baby is *really* the center, and we manipulate our systems to help that little boy or girl to develop . . . The only difference may be that whatever it is we each are doing, we are doing it together . . . better than we have ever done it before.

PARENTS ARE EDUCATORS, TOO

Twenty-five years ago, children with Down's Syndrome were considered by many mental retardation professionals to be "no program kids"—children who could not benefit from any form of educational instruction. They were expected to be jolly boys and girls who would not live very long; their parents were often believed to be traumatized, incapable of doing anything about their child's intellectual development. The professionals who held these beliefs—and a great many of them did—considered it unthinkable that they should share their educational skills in such a hopeless cause. That, however, was 25 years ago . . .

Down's Syndrome Infant-Parent Program. The Center on Human Development, University of Oregon, Eugene Oregon.

Three years ago, a young teacher began traveling from 500 to 600 miles a week throughout western Oregon to 12 families with newborn Down's Syndrome infants. Her task: to carry out a special BEH-funded research training program that, unlike most research programs, would take place in the home with the parents serving as the "research assistants."

The teacher possessed a combination of knowledge and vivaciousness that made her attractive to the families. She had a thorough understanding of the breakthroughs in early childhood education that had been taking place at the University of Washington's Experimental Education Unit; the University of Miami's Mailman Center for Child Development; Teaching Research in Monmouth, Oregon; Cooperative Educational Service Agency #12 in Portage, Wisconsin; and Lincoln Center in Chapel Hill, North Carolina. It was her goal to take the breakthroughs achieved at these five centers and apply them in the home setting.

It wasn't easy. In the beginning, most of the parents had low expectations for their mentally retarded infants and for what they could do to help their children learn. The teacher was a nice lady, they felt, and it was pleasant having her visit, but they were skeptical about how she could be of any help. Three years later, the situation had changed dramatically. The children were functioning close to the developmental milestones of normal children; and the parents had acquired confidence and skill in working with handicapped boys and girls. More than that: the parents possessed documentation, written by themselves—to prove the success of the program.

The program contained some crucial ingredients:

- *Developmental Milestones of Normal Children* (e.g., when they hold their head up, roll over, crawl, stand up, walk, talk and feed themselves).

The Family

The parents were taught to recognize these milestones and to compare them with the developmental accomplishments of their handicapped child. The primary goal of the parents was to help their child function as close to the normal milestone as possible.

The Home as Educational Resource Center. The parents were encouraged to view the everyday events and physical effects of the home as a goldmine of educational opportunities and devices just waiting to be discovered. Familiar events could be broken down into sequential steps for learning, while the physical things around the home could be fashioned into prosthetic aids. Once parents learned to see their home as a rich educational resource center, they no longer felt that their child's education must take place in a special building stocked with special equipment.

The Teacher as Responder. As soon as parents became alert to normal developmental milestones and the potential of their home as an educational setting, the teacher, visiting once a week, was in an excellent position to perform a single, helpful function. For example, when parents expressed the wish to help their child learn to roll over, the teacher first took into consideration the home resources, events, materials and people involved. She then wrote a step-by-step plan for helping the child to roll over. However, the family was given the responsibility for deciding what had to be taught—and they did the teaching.

- *Record Keeping.* Recording data on a child's behavior and accomplishments can be a dreary affair, but this teacher managed to make it interesting. She trained parents to use a remarkably simple system for recording how an infant succeeds in accomplishing a single step. The system consists of listing, for each day, the numbers 1 to 10 (the number of attempts to teach an infant a single behavioral step). The parent places a plus sign (for success) or a minus sign (for failure) next to each numbered attempt, and then totals the number of successes for the day. Here, for example, is the checklist used while Angie was being taught to feed herself. The checklist is concerned specifically with helping Angie learn to reach.

TARGET SKILL: ***Reaching***

Date:

5/1	5/2	5/3	5/4	5/5	5/6	5/7
+ 10	+ 10	+ 10	+ 10	+ 10	10	10
+ 9	+ 9	+ 9	+ 9	+ 9	9	9
+ 8	+ 8	+ 8	+ 8	+ 8	8	8
− 7	+ 7	+ 7	+ 7	+ 7	7	7
− 6	− 6	+ 6	+ 6	+ 6	6	6
+ 5	+ 5	+ 5	+ 5	+ 5	5	5
− 4	+ 4	+ 4	+ 4	+ 4	4	4
− 3	+ 3	+ 3	− 3	+ 3	3	3
+ 2	− 2	+ 2	− 2	+ 2	2	2
+ 1	− 1	− 1	+ 1	+ 1	1	1
0	0	0	0	0	0	0

On May 1, Angie was helped to reach for a piece of food 10 times. The assistance given could be a full hand prompt (bringing the hand to the food), a wrist prompt, an elbow guide, or no assistance at all. Each time Angie reached for the food unassisted, one or more family members responded warmly (planned reinforcements of success) and a plus sign was placed next to the number of her attempt. If she needed assistance, a minus sign was placed next to the number. The record shows that on May 1, Angie reached for the food without assistance on the first, second, fifth, eighth, ninth and tenth tries. The other tries were all failures. The number 6 was circled to signify the number of successes for the day. On May 2, Angie was successful seven times; on May 3 and 4, she scored eight each day; and on May 5, she had a perfect score.

The procedure was so simple that fathers, brothers, sisters, grandparents and even neighbors became involved. The net result of this widespread involvement was that mothers were not left alone with such problems as much as they had been before.

Two and one-half years after this program began, all 12 of the children had reached developmental milestones remarkably close to those of normal children. Without help, it would have taken them many months longer. For example, a normal child holds his or her head up at about five months. All 12 of these children were doing it before five months, while other Down's Syndrome children, with no intervention, usually do not accomplish it until some time in the second year. There were many similar successes.

The teacher and her "research assistants" developed their own graphs to show how their children compared with normal children and with Down's Syndrome children who had received no intervention.

A number of interesting features have emerged from this project:

- Except for demonstrating and modeling, the parents do all the teaching.
- The parents make the final decision as to what their child needs to learn next.
- As parents begin to feel confident about what they are doing, visits by the teacher are reduced.
- The measurement of accelerating development becomes an exciting motivator for the parents.
- There is no need for a carry-over from the classroom, since all learning takes place within the home.
- Parents in the program experience less grief over having a retarded child than do most parents in the same situation.

Reprinted from Hanson, Marci. *Teaching Your Down's Syndrome Infant: A Guide for Parents.* Baltimore: University Park Press, 1978.

As the program continued, the original teacher moved on to a coordinator's position and another teacher picked up where she left off. The parents continued as they had before: watching the normal developmental milestones, prompting their children, reinforcing the steps already learned and recording each success and failure.

Today, some of the children are ahead of normal development in many areas. Three-year-old Tony, for example, knows his colors, counts to seven, does one-to-one correspondence, engages in rational counting and has made initial steps in writing. It has all been done through regular, playful interactions with this family.

The results—as amazing as they seem to be—are being received with a tempered view. The parents and teachers know that there are limits to their children's development and that when they are of school age, the normal children will develop with greater ease. The goal at present is only to help these Down's Syndrome children get a running start. Nevertheless, these children have already accomplished far more than was thought possible 25 years ago. How much more they will accomplish is still anybody's guess, but it would be a mistake to sell them, their parents or their teachers short.

IN-HOME CARE WHEN IT IS NEEDED

Parents of older mentally retarded persons can tell of harrowing experiences in the not-too-distant past when they requested help from health, education and welfare professionals. Often, the only answer they received was: "Send him to an institution." One pediatrician in Washington State recently commented, "When I reminisce about how we, the professionals, used to deal with such families, it strikes me that we were utterly brilliant at separating mothers and fathers from their mentally retarded children." Such "brilliance" still exists today, of course, but it is definitely diminishing.

The Home-Aid Resources Program of Washington Bureau of Developmental Disabilities, Olympia, Washington.

When a request for help comes from the home of a mentally retarded person in this state, everyone listens—or so it seems. The state's Bureau of Developmental Disabilities (BDD) stands ready with an impressive array of in-home resources: respite care, therapy services, program skill development and government subsidized parent-to-parent contacts. Nor is it just the professionals who are sensitive to such family needs. Last year, the state legislators voted to increase funding for Home-Aid Resources from $760,000 to $1,010,000 *without a budget request from the agency.* The University of Washington and The American Red Cross have both gotten into the act by training home-aid providers. And if by chance a parent's request for help receives no response, the state has an efficient system of red tape-cutting advocates who make sure the parent's request is heard (see "The Troubleshooters" in this section).

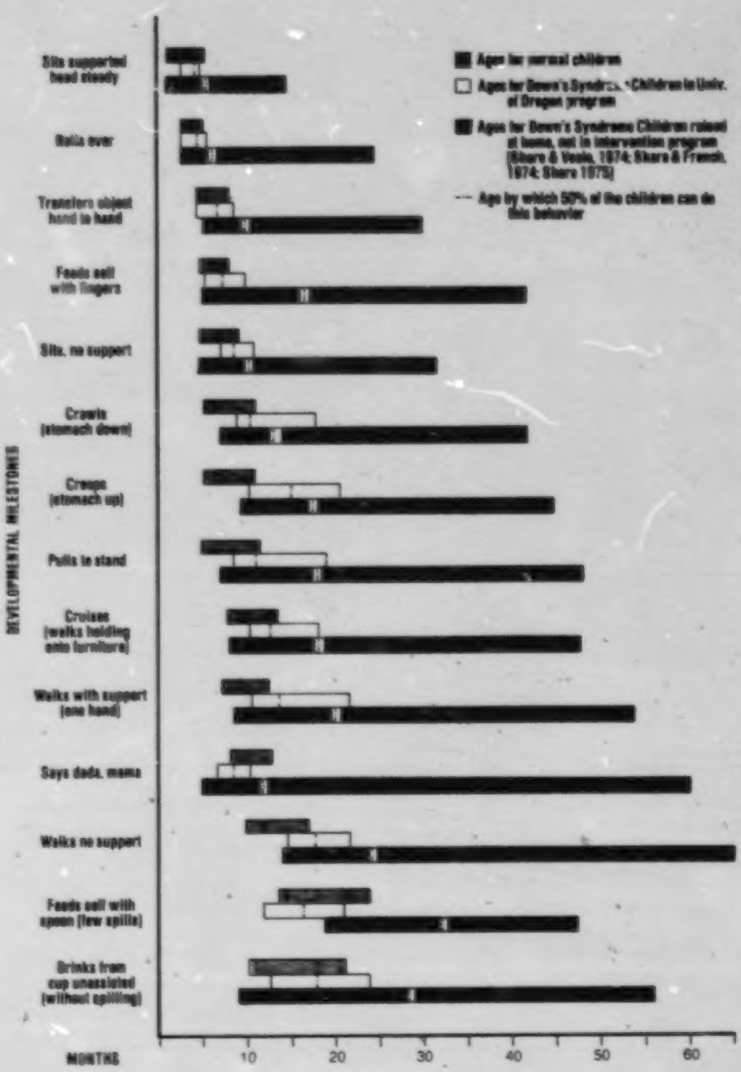
All of these efforts to get early and efficient help to parents of mentally retarded children stem from the state's massive effort to preserve such families and make them strong. The practice of quietly and quickly taking retarded children away from their families has ceased in Washington. BDD is committed to this new approach and has put it in writing as the agency's single, underlying goal: "Home-aid services are provided with the specific intent of eliminating or reducing the need for placing clients into residential settings which are more restrictive than the community/home environments." (BDD Report, February, 1977)

The efficiency of the Home-Aid Resources Program is phenomenal. Only 1.3 percent of the funding is used in the overhead while 98.7 percent goes directly for in-home services. This is accomplished because no intermediate service organization is used in the process. The state contracts directly with each person providing the services and mails the check to his or her home.

The program offers a number of distinctive services to mentally retarded persons and their families.

Better than 75 percent of the home-aid budget is used for this crucial program which provides regular or emergency in-home services. Although this is by far the most popular type of service offered, out-of-home planned and emergency services are available as well.

The mechanism a family uses to get respite care is as follows: (1) The family makes a request for help to one of BDD's six regional or 16 satellite offices which are located throughout the state. (2) A member of a regional team evaluates the situation and authorizes either a number of respite care hours per week or sufficient services to offset an emer-



Reprinted from Hanson, Marci. *Teaching Your Down's Syndrome Infant: A Guide for Parents.* Baltimore: University Park Press, 1978.

gency. (3) The region provides a list of respite care providers from which parents can choose. Parents can, if they wish, select a provider from their own community; however, in such cases, it is recommended that the provider complete a thorough, competency-based training program which is offered free of charge. (4) If the provider has not done so previously, he or she signs a contract for services with the state. (5) Each month the parents sign the provider's statement of hours worked and it is submitted to the state for payment. (6) The check is mailed to the provider's home. The hourly rate of payment varies with the intensity of the person's handicap and the type of service provided.

- *Resource Therapies.* Certified therapists are contracted for in-home services when no other agency in the community can provide the required help. Therapists are contracted for physical therapy, occupational therapy, recreational therapy, nutrition and health maintenance, dental hygiene, medical prevention and maintenance, behavioral management, intensive one-to-one programs, communications therapy and other therapies. These therapists are certified by the state, and payment procedures are identical with those used for respite care providers.
- *Parent-to-Parent Outreach.* In some cases, a veteran parent of a handicapped child is assigned as a peer group counselor to parents who have recently had a child with the same type of handicap. Parents who have been assigned to help other parents can receive payment for mileage and sometimes for the time spent in counseling. Many of these skilled persons, however, volunteer their services.
- *Transportation Support.* Payment for transportation is provided for all respite care providers and therapists who must travel 25 miles or more to provide the in-home services.
- *Specialized Equipment.* The program purchases special prosthetic devices and other items needed by a handicapped person in cases where other community agencies are not able to do so.

The success of the Home-Aid Resources Program is greatly enhanced by two non-governmental groups which collaborate with the BDD in training respite care providers. They are the University of Washington and the Red Cross.

The University's College of Education has developed a 30-hour training program that includes the Red Cross first aid course and sessions on the following 10 subjects: understanding the developmentally disabled person; the family situation; home safety; medical management; mealtime management; communication; physical management; behavioral management; dressing and toilet training; and leisure time activities.

The state Red Cross chapters have provided space and utilities for the project training office as well as for classrooms throughout the state. The national office of the Red Cross has contributed additional funds and expert advice. The sum total of all these efforts has been a training program so successful that it is now being made into a certified, competency-based program similar to the Red Cross' programs for swimming, lifesaving and first aid. Materials and manuals are being developed for three training levels: care providers, instructors and advanced instructors. All training must measure up to the Red Cross' high standards and providers receiving certification must demonstrate competency at a required level.

Although the home-aid program was developed by the state, its shape has been greatly influenced by the lobbying efforts of a strong consumer advocacy force of voluntary associations and the aforementioned "Troubleshooters." These advocates remain on constant alert, discovering breakdowns in the system and exposing failures whenever they are found. Such no-nonsense consumer monitoring provides a steady balance of power that keeps the Home-Aid Resources Program developing at optimum efficiency.

Some interesting findings have emerged from the state's efforts to aid the families of the mentally retarded:

- *Home-aid privileges are seldom abused.* For example, the mother of a seven-year-old, profoundly handicapped daughter had been forced to stay in the home almost 24 hours a day. When she applied for help, she was authorized nine hours per week and one weekend per month for in-home services. Although she speaks enthusiastically about the first time she got away to watch one of her sons play soccer, she has yet to use her weekend privileges because she feels she doesn't need them.
- *The training program has become popular.* Parents of mentally retarded persons and other interested citizens are now taking the respite care training course with the providers. In Tacoma, the head of the public school nurses is working on a program whereby 40 school nurses can achieve instructor's status; they, in turn, will teach the course as an elective in high school.
- *Security is knowing there is someone to call.* Said one mother: "You don't know how good it feels to know that Home-Aid Resources are available if I need them. I may never have to use them again, but knowing they are there is comforting, and it keeps me going."
- *The needs of rural families are different.* Service delivery records show that rural families do not use respite care services as much as do urban families. However, they use more of the in-home therapies than do their city counterparts.

- *Home-aid service is not an isolated effort.* The BDD regional offices are now offering other services in addition to home-aid; for example—case management, individual program planning, vocational services and recreational services.

Home-aid is considered the "first wave of services" that need to be delivered to families with mentally retarded children. But it is not enough just to deliver them; they must be made available as early as possible after the family's request is heard. This, of course, is not an easy task for any state to carry out, but the State of Washington has proven that it can be done when a service delivery agency, a university, the Red Cross and a group of consumer monitors tackle the problem together.

TEAMWORK IN THE BRONX

The hardships that come with having a mentally retarded child are greater when you are poor, and when you speak a foreign language. If this is your situation, then you may be faced with two options typical of 1940: Either you send your child away, or you keep him at home and receive no support. Nineteen-forty was not a good year for most mentally retarded persons. And if you happen to live in an economically depressed area of the United States, today may be not much better.

However, some courageous people have begun vigorous programs with families of mentally retarded persons in environments where the economy is bleak. If this new breed of professional and paraprofessional are successful with their imaginative approaches, the vintage treatment of 1940 may soon disappear.

The South Bronx Community Services Team, The Bronx, New York.

The team's tiny office stands three blocks away from where President Carter and Patricia Harris, Director of Housing and Urban Development (HUD), stood October 5, 1977, to survey "a wasteland of burned out buildings." When you walk into the office, you find no elegant facilities or equipment, no sophisticated mannerisms that can be observed in wealthier sections of the nation. But you quickly learn that the members of the South Bronx Community Services Team (SBCST) have heart. They are uncanny at finding families with retarded persons and getting them the crucial services they need.

SBCST and many other small units came into being shortly after the State of New York began plans for the Bronx State School, a large multi-bed institution which would have become the residential catchment net for many retarded persons who live in this crowded borough of 1.4 million human beings. But the school was never built; the leaders changed their minds and decided to move in radical new directions. A modified building, the Bronx Developmental Center, was constructed with apartment-style living quarters, where a far smaller number of retarded persons live for short, intensive training periods. (The date of their discharge is planned and agreed upon before admission.) The remainder of the building houses the head offices of the Bronx Developmental Services (BDS) and facilities for a wide array of day programs for developmentally disabled children and adults.

The most striking change in plans has to do with the staff. Many of the professionals and paraprofessionals who would have otherwise been putting all their energies into keeping a central institutional system alive, have now been placed under BDS. They have been organized into many small service units, scattered throughout the borough. Although each unit serves a different function, they all follow a set of guidelines calling for the comprehensive delivery of services to people in the many neighborhoods. When the director of BDS was asked how these decentralized, highly accessible, quick-to-respond units worked, he replied, "We don't homogenize anything. We give specific guidelines to small units and we send them into assigned neighborhoods to do their thing . . . We have some good people out there who are able to go into new, uncharted territories and do things that have never been done before . . . What's more, better than half of even our middle management live in the area where they work."

The SBCST is one of more than 20 small units at work in the neighborhoods. There are also five other community service teams serving geographical areas, and still other units (e.g., the Apartment Living Program, the Travel Training Program, the Rehabilitation Team, the Early Intervention Program, etc.) move in and out of neighborhoods as their special services are needed.

Since the style of life varies in each service area of the Bronx, the style of the teams varies, too. "There is a great difference between the South Bronx Team, serving many Hispanic residents, and the Southeast Team that serves a stable, Italian neighborhood," the director says. "That's why each team, to be helpful and efficient, must be allowed to be creative on its own in a decentralized atmosphere . . . If we tried to develop a homogenized, bureaucratic system covering all of the Bronx, we would crush to death the thriving creativity of the teams." Thus, the SBCST carries out its own inimitable functions as dictated by the needs of its clients. Some examples:

Finding families with retarded persons has developed into a fine art with many of the teams. The workers learn about families while walking the streets and while conversing with people in the neighborhoods.

Winning trust takes time and patience. Many government workers who had previously served in the area recommended that families send their handicapped relatives away. Such a thought is abhorrent to the average Hispanic citizen. It only increases families' fear, forcing them to overprotect the handicapped individual, shielding them closer within the home. It takes time for an SBCST worker to convince a family that the goal is to strengthen and support the mentally retarded person within the home setting.

Keeping track of clients can be an extremely difficult business. Since families must often abandon buildings due to condemnation, disrepair and fire, it is easy for clients to drop out of sight in the vastness of New York City. The workers have learned how to find these people by taking to the streets.

In dealing with HUD, the team member often speaks as an advocate for the family. *Estrelita is not violent just because the application says she is retarded . . . Maria is not a child; she's 45 years old and needs her own room . . . Pablo is non-ambulatory, so you could be a great help to him if you allowed him to move from the fifth floor to the first . . .* The Supplemental Security Income (SSI) process is one through which almost every family must be guided step by step. Recently, the SBCST took a significant step forward when it arranged for social service workers in charge of SSI to schedule days at the two team offices. Now, handicapped clients or their families are brought in on these scheduled days to carry out the SSI process in a familiar setting. Team members are available as advocates and interpreters.

Getting a handicapped child into school can be an uphill battle requiring many steps: (1) Formal application must be made with the Board of Education; (2) the family must respond to a letter from the board which sets an appointment date; (3) the child must undergo an evaluation; (4) the Board of Education's Committee on the Handicapped must certify the eligibility of the child; (5) the child is placed on a waiting list. The failure of parents or case managers to keep calling results in no school for the child. Most children would never get into school without SBCST members transporting them to meetings and monitoring the process. This past year, 100 handicapped children were found needing a public school education. Today, almost all are attending school; those who are not are on the waiting list.

Twelve profoundly handicapped adults were found in homes with absolutely no training program or support. Many had been overprotected by families who did not know what else to do. As a last resort, the team developed a day training program for them. SBCST staff members and a public school teacher on assignment joined together to deliver a six-hours-a-day instructional program on grooming, hygiene, aid to daily living skills, socialization, communication and

pre-vocational training. Today, there is striking growth and development in all 12 adults; their lives are happier. The same can be said for the families who have been freed from a burden which they carried in painful silence for many years.

SBCST workers have become effective "synthesizers of services" on behalf of their clients. They identify crucial needs and, with a special knack, work at getting service agencies throughout the borough to supply the required services. Much help has been given by the Einstein College of Medicine, The Rose F. Kennedy Center for Research in Mental Retardation and Development, and the University Affiliated Facility (UAF) at Yeshiva University. These organizations have been heartwarmingly generous in their services to BDS clients.

A halfway house for clients being returned to the community from the Willowbrook Developmental Center is now operational in cooperation with the Metropolitan Placement Unit, the agency in charge of transferring such residents to the community.

Two homemakers assigned from a commercial homemaker agency (which holds the contract for services to the city) render 80 hours of in-home services a week to SBCST families. Arrangements were made with the corporation to screen and provide special training in developmental disabilities for the two homemakers. Both have been accepted as members of the team, although their salaries are paid by a commercial corporation.

SBCST has worked with the Board of Education in starting developmental programs. Public school teachers are supplied by the Board of Education, while the team hires and trains the teacher aides.

Couple the above activities with all of the usual activities of a community service team (e.g., vocational training, parent counseling, psychological testing, recreation and leisure time activities, etc.)—and remember to take into account that all of this is accomplished in one of the most difficult places in the nation for finding and serving retarded citizens—and you have a better-than-fair idea of what the South Bronx team is all about.

The team's strength and creativity lies largely in its ability to decentralize and create services in neighborhoods. This channeling of service delivery, plus the team's energy and enthusiasm, has resulted in over 5000 visits to homes this past year and in the delivery of approximately 135,000 specific services. The visits and services will be at least 25 percent higher this year. With results like these, it is possible that the Bronx, in spite of all of its problems, will provide significant service delivery concepts which other, more fortunate communities in the nation can use to good advantage.

SALVAGED DESTINIES

"Every child is dependent upon whether other men care for his destiny." These words, used in a brochure of the agency described below, are hopeful words. We like to think of them as applying to our children, to our neighbor's children, to all of the children in school everywhere. But how rarely are they applied to the profoundly handicapped children—the youngsters who suffer from various combinations of mental retardation, cerebral palsy, epilepsy, autism, blindness and deafness. Hopeful words for "hopeless" cases? The idea that such children do have a destiny, just like the rest of us, has often been ignored by mankind.

The Somerset Home School, Carmichael, California

The staff members of this training home work hard, helping others with disintegrating destinies before it is too late. First, they focus on the directions of six profoundly handicapped children (ages, from birth to six years); later, they expand their attention to the children's families. Salvaging destinies is their business.

Frail, multi-handicapped children come into a three-acre wonderland of sensory stimulation and the reinforcement of healthy responses to it. The house is filled with bright colors, harmonious music, restful waterbeds, voices with loving tones, hands that massage, arms that hold one close, the stimulating waters of a Jacuzzi whirlpool, the smell of baking bread and a noisy canary. Outside is the sun, fresh air, a swimming pool, two spirited horses, a gentle pony, goats, dogs, cats, a rabbit and a duck. All play an important part in giving direction to these children's lives.

It all began five years ago when Tom and Sunny Whalley, the parents of a profoundly handicapped child and two teenage daughters, moved to a larger house. They hired extra staff and opened their home as a 24-hour training unit for their son and five other profoundly handicapped children in the area.

The purposes of the unit are simple: to receive profoundly handicapped infants at Somerset for a brief period of time; to perform every early childhood intervention which is appropriate; to slowly phase the child's family into the program; and to send a stronger, more valued child back to his or her home, where a healthier family-child bonding can take place.

The staff of Somerset is very much a family affair: Tom is the administrator, Sunny is program director, four hand-picked child care workers carry out the scheduled activities and the couple's two teenaged daughters assist when they can. Backup support is provided by a registered nurse, nutritionist, and case worker of the Alta California Regional Center, Sacramento. Also a physical therapist in private practice works regularly at the home.

The program is intense and extremely humane. It is heavily influenced by the concepts of Rudolf Steiner, who years ago spoke of the value and dignity of profoundly handicapped persons. Detailed interventions of Neurodevelopmental Training (NDT) are carried out faithfully. For example, body positioning and head control programs continue all day. The jerky infantile reflexes—so important at birth but an impediment to growth if they fail to diminish—are helped to fade, while the purposeful use of lips, tongue and jaw are stimulated and reinforced. Events like mealtimes are unhurried, relaxed, enjoyable communions between big people and little ones.

All children have daily periods in the water. Three have been taught to hold their breath and swim underwater. The "champ" is four-year-old Susie, who is blind, has cerebral palsy and static seizures. She can glide underwater for 10 feet, kicking and paddling from one person to another. Such a feat is a striking exercise in trust! Additional time is spent each day in the Jacuzzi whirlpool, one of many means used to develop muscle tone.

All efforts are geared to helping the children move from weakness to strength, from negative behaviors to purposeful interactions with the world around them. Their progress is measured by precision charting of behaviors, as well as by monthly videotapes.

In happy contrast to so many institutions, where handicapped patients are hidden away from the public, the doors at Somerset are open to the community. Normal children are invited into the home and interact with the handicapped children by playing with them, swimming together, riding ponies and enjoying group picnics. Local musicians are frequent visitors to the house, too, for there is a great love of music at Somerset. The rooms are often filled with music—sometimes played by the musicians in informal concerts, sometimes from Somerset's record collection.

Photos by Pat Henry

As parents increase their involvement with their own handicapped children, their attitudes frequently change. Many parents become avid consumer advocates, joining with others to start vital services for multi-handicapped persons in their own communities. They know the time is approaching when their child will need some of those services as well.

Last year, the Somerset Home School received the Award for Excellence from the California Commission on Developmental Services. Two years ago, the agency underwent the California Department of Health's ANDI (A Normalization and Development Instrument) Accreditation Survey.[1] Surveyors reported that Somerset had received one of the highest ratings in the state. Although the award and the accreditation rating are appreciated, staff members name other high moments which mean more to them. One such moment came from watching little Marie and Jimmy thrive and develop after they had been given little chance to live; another, from seeing parents mobilize their own strengths, develop their own skills and make the adjustments necessary for bringing their child back into their own home.

Soon there will be three home schools operating instead of one. Other properties are being acquired in the region, and two young couples are being prepared to move into the homes and begin programs similar to those at Somerset.

There is hope for the mentally retarded when the parents of such children—people like the Whalleys—refuse to accept what others believe about their handicapped child. In this case, a family has ignored the pessimistic presumption that profoundly handicapped children must be written off as having no future at all. Instead, they began work with their son—and with others like him—and they have documented, in film and written records, the rich, step-by-step developmental climb each child has made. And as these children developed, their parents, becoming more stalwart and caring, found new directions. Salvaging destinies is a supremely difficult business, but it can be done. In fact, it can be done by only two people who really care.

[1] ANDI combines the key components from two national accreditation efforts. The Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons (AC MRDD), and Program Analysis for Service Systems. (PASS)

PARENTS TO PARENTS

Parents of retarded children have reported how they suddenly began feeling apart from everyone else after learning of their child's handicap. They thought of themselves as being different and alone, almost as if they were one of a kind. Neighbors coming to them with information and advice seemed to stand at the edge of their struggle. Even service providers were seen to some extent as "outsiders," since they had not gone through the struggle themselves. Often, it took another parent of a retarded child—one who had "been there"—to reach the isolated parents and help them understand that they and their handicapped child were valuable members of the human race.

Pilot Parents, The Greater Omaha Association for Retarded Citizens,
Omaha, Nebraska

In this city, a parent with a developmentally disabled child can call for assistance from another parent who has successfully adjusted to the same problem. The idea that parents of retarded persons are good at helping one another is not new; however, the speed and efficiency with which Omaha parents help one another is remarkably fresh: Put in a request for assistance through Pilot Parents and parent-to-parent contact will be made within 24 hours. The Greater Omaha Association for Retarded Citizens, recognizing the value of on-the-spot parent helpfulness, has organized some of the community's best fathers and mothers of handicapped children into a powerful system of peer group education and support.

Although Pilot Parents are not formal counselors, nor case managers, they offer peer group interactions based on their own experiences and knowledge. They know what it is like to have a handicapped child; to receive "mixed signals" from relatives, friends and neighbors; to have some doctors and dentists passively or overtly reject their handicapped child. (Pilot Parents keeps a list of physicians and dentists who have been helpful and understanding, and those who have not.)

One Pilot Parent used this analogy to describe what the organization does:

> We are like harbor pilots who guide ships out of strange harbors. The harbor pilot knows all the danger spots because he's been there before. He helps the captain steer around them until the ship is ready to move safely on its course.

Quite often, a Pilot Parent and the parent who is aided develop close friendships that last long after the original period of service. Such peer group education seems to be powerful because there is a strong hunger within us to learn from someone involved in the same experience.

Becoming a Pilot Parent has its involvements and its time limits. A parent begins by making a formal application to serve for one year at a time. Although the application contains the usual questions, it also contains components seeking the applicant's own evaluation of his or her family's adjustment to a handicapped child. Screening and training involve six evening sessions on the following subjects: An orientation to the Pilot Parent service effort; the family's adjustment to a handicapped child; the use of the Program Analysis of Service Systems (PASS) evaluation process, based on the principles of normalization; and a thorough description of all community service agencies for developmentally disabled persons in the region. Throughout their one-year tour of service, Pilot Parents attend monthly meetings designed for information exchange and additional educational input.

When a family calls or is referred for peer assistance, a detailed in-office process goes into effect. Information on the family and their needs is gained through a low key but structured telephone conversation. A short time later, a list of available Pilot Parents is consulted and a parent whose child has similar disabilities is chosen to make contact. Two days later, feedback on the visit is phoned into the office. Decisions are made at that time about the nature of the on going peer assistance process, which is shaped to the needs of the situation.

Many dramatic outcomes have resulted from these peer group interactions:

- An 18-year-old mother was helped to decide to take her newborn son home from the hospital after the physician had given the child a diagnosis of Down's Syndrome and suggested the baby be sent directly to the institution. (A nurse on the ward notified Pilot Parents.)
- Another mother received much needed respite care for her two-year-old retarded son when the Pilot Parent found her emotionally exhausted after a painful, three-week struggle and final separation from her husband.
- One piloted couple, whose handicapped child died, has applied for Pilot Parent training, hoping to be assigned to other parents whose children are not expected to live.

Many parents are helped to find services for their children; and when services are not available, the Pilot Parents become advocates, fighting for what is needed. As this happens, a powerful consumer advocacy effort remains alive, providing a balance of power that is capable of questioning agency officials, exposing inefficiency and keeping service delivery workers on their toes.

Today, the roster contains 45 Pilot Parents of children with a wide array of developmental disabilities. Sixteen have developed from being receivers of peer assistance to being givers of it. Twenty-three are on call to speak about Pilot Parents in Omaha's clubs and classrooms.

Social functions are held regularly so that the parents and their children can get together. Each social function adds its own richness to the program. At happy occasions—like picnics, holiday parties, coffee meetings and cocktail parties—parents caught in grim situations are helped to laugh again. Pilot Parents often possess a zest for living and an ability to share it with others.

As specific needs arise from the chemistry of peer group relationships, small groups of Pilot Parents take on added projects. Some examples:

- One group found that most of the books on mental retardation written prior to 1970 were outdated, so they wrote a proposal to the State DD Council asking for money to purchase and catalog books for a lending library for parents. The proposal was granted and the project was carried out.
- Another group felt the need to get the latest information to physicians, so they had printed attractive file folders, suitable for filing in a physician's office, which contained information for both the physician and his patients. Brochures which could be given to parents of developmentally disabled children were included. The Pilot Parents replenish the supply as doctors give the materials to parents who need them.
- Attractive file folders similar to those given to physicians are placed in the many children's wards of the city's hospitals. Posters explaining the Pilot Parent program and the telephone number to call are placed on hospital bulletin boards.

The credibility of the organization has increased greatly. Many physicians and hospital personnel advise parents to call for peer assistance. The in-home staff of the Visiting Nurses Association and the counselors of the Eastern Nebraska Office of Retardation not only provide ample input to the training of Pilot Parents, they also often work as teams on certain cases. Pilot Parents work with agencies for persons having cerebral palsy, autism and epilepsy, too.

Recently, the Pilot Parents of the Greater Omaha area received a grant from the Regional Developmental Disabilities Office to send teams into Missouri, Kansas, Iowa and other parts of Nebraska to help 10 communities develop their own Pilot Parent programs. The Omaha group has already received requests for such assistance from 22 communities throughout the four-state area. Thus far, the group has developed seven new programs—and they don't intend to stop until all 22 are trained and running well.

PARENTS AS PROFESSIONALS

Services to mentally retarded citizens can be endangered at any time when decisions about such services are removed from clients and their families and handed over to experts and bureaucrats who are far removed from the actual services being delivered. Although consumer participation can be uncomfortable to the entrenched bureaucrat, such involvement contributes much to an agency's ability to meet the real needs of handicapped persons and their families.

Recent federal legislation having to do with education (The Right to Education for All Handicapped Act) and habilitation (The Developmental Disability Act) calls for strong consumer participation in the individual planning process. A number of states have also adopted consumer-oriented legislation. California's Lanterman Act, which offers a remarkable number of opportunities for creative consumer input, is a good example.

The Regional Center of Orange County, Orange, California

While agencies throughout the nation are training and assigning professional program coordinators, this center makes it possible for a parent to train for the job. This parent-as-a-professional arrangement is based on a point of state law which has frequently been ignored: "Nothing shall prevent a person with developmental disabilities or such person's parent, legal guardian or conservator from being the program coordinator of the person's individual program plan (IPP)." [Chapter 1368, The Lanterman Act of 1977, The State of California]. The law makes the process sound easy, but actually it is not. The course a parent takes to become the program coordinator for his or her own child is rigorous—so much so, in fact, that many do not complete the training program.

Parents begin by making formal written application for the position of program coordinator for their children. After they have been accepted, the "trainees" move through a three-phase program.

Phase one is a formal, 10-week training program coordinated by Rancho Santiago Community College. The course includes three hours of lectures per week on such topics as the history of the regional center system; the program coordinator's relationship with the regional center; writing and recording skills (e.g., individual program plans, data based records, quarterly and annual review records); the intake process; placement practices; orientation to all resources and agencies; the law (e.g., client's rights, parents' rights, guardianship and legal issues); and systems for recognizing growth and development. A final examination is given at the end of the course.

Phase Two is a one-year apprenticeship called "conjoint programming." In this phase, the parent and a professional work together, applying the information learned in Phase One. As a team, they carry out all the details of programming for the parent's child.

If all goes well during the apprentice year, the parent moves into the Solo Phase. In this phase, the parent functions as a member of the regional

center team; conducts the annual review as team leader on his or her own child; synthesizes all team efforts and writes the IPP; writes the quarterly and annual reports; arranges for the purchase of service contracts and seeks final approval from the center's unit manager; and receives the customary administrative, professional and clerical support accorded any program coordinator.

Although the program has been operating for a little less than two years, the following results have been produced:

To date, 75 parents have completed Phase One, while 35 are in Phase Two apprenticeships and 15 are Solo Phase program coordinators.

Over half are parents of adults. "This was most surprising," a regional center supervisor said, "but now we understand why it happened. These parents lived through a period when their children had no programs at all, and nothing could have been done about it. Now, the chance to coordinate their own adult child's program has proven to be an attractive option for them."

Better than half of the parents have children in an institution. In California, each regional center is responsible for the development of the IPP and program coordination for developmentally disabled persons in institutions as well. Consequently, parents of institutionalized persons have a chance, for the first time, to assist with their child's program.

Many of the parents' case presentations, individual program plans and written reports are extremely professional. This became understandable when it dawned on the staff and parents that the average program coordinator has a case load of 60, while a parent-coordinator can work long hours on a single case.

In Phase Two, both the parent and the professional invest an average of from 10 to 15 hours per month working together on a single program. By the sixth month, the time spent together lessens. This shift is seen as evidence of growth in the parent.

Many "tough" parents who have repeatedly exhibited anger for the delivery system have applied for training as parent coordinators. The formal education and close relationship with a professional have been invaluable in understanding the other person's point of view. Many such parents are on the road toward becoming efficient, responsible coordinators of their children's programs.

Since parents of developmentally disabled persons, like all of us, have varying degrees of talent and energy, it is clear that all parents will not and should not undertake such a program. Nevertheless, in creating the parent-coordinator program, the Regional Center of Orange County has come up with one more consumer activity which can be added to a long list of parent involvement choices emerging throughout the nation.

With each new consumer effort, there is less chance that decisions affecting the future of mentally retarded persons will be made in remote agency offices by people who will never know their "cases" personally. Instead, relevant decisions will be made out in the open—by parents who have demonstrated their competency to decide.

TROUBLESHOOTING IN WASHINGTON STATE

In the views of many advocates, no agency can be presumed to be honest or efficient in their delivery of services to families with mentally retarded children. For example, an agency may describe in glowing terms what is being accomplished for mentally retarded persons, while the families trying to get the services suffer frustration from what they didn't get and disappointment with what they did get. Or the agency may say sanctimoniously how badly it needs monitoring by the consumers, but when that monitoring is forthcoming, the agency finds 1001 ways to quiet the consumers and put them down.

Many service delivery experts have come to see that an agency is kept honest and efficient when a balance of power with an ability to expose unresponsiveness is provided by coalitions of consumers who do not give in easily.

The Troubleshooters, Seattle, Washington.

These advocates know all about the confusing application forms, the slow-moving machinery of bureaus and the picayune reasons for denial of services which parents of retarded children often suffer in their attempts to get help. They not only know about it, they do something about it. This family advocacy agency swings into action with the dialing of a telephone, ready to listen to a parent's problem; to help them move, step by step, through a procedural maze; and, when necessary, to confront and expose an agency's derelict unresponsiveness to a family's needs. The advocates are called Troubleshooters and there are 40 of them operating out of 24 offices throughout the state.

The Troubleshooters had a modest beginning. In 1972, two parents made an agreement with Seattle's Northwest center for the Retarded—the agency where their adult children attended—to develop a manual on "how to get benefits for disabled adults." The office management was funded by a small grant from the regional HEW Developmental Disabilities Office, and the two parents agreed to volunteer their services.

Their plan was simple. First, they would attempt to move through some of the service-getting processes as parents of adult mentally retarded children. Then, they planned to write out guidelines and steps that other parents could follow. However, after one month of attempting to move through the system, they were overwhelmed by the obstacles and degradation they encountered. "We found we were caught up in systems never designed for us and they simply didn't work," says one of the parents. "So we decided to help families individually and to work on the systems at the same time."

During the next three years, a system for helping individual families who called on a special Troubleshooters telephone line was developed by the two parents and their office manager. At the same time, they joined with the state Developmental Disabilities Planning Council in building a variety of coalitions which began to provoke changes in all of the public assistance delivery systems for developmentally disabled persons.

In 1976, the Troubleshooters became an independent family advocacy agency, and the governor called for the setting up of four Troubleshooters offices in other areas of the state. The new Troubleshooters were salaried by the Comprehensive Employment and Training Act (CETA) and their training was supplied free of charge by the veteran Troubleshooters of Seattle.

In 1977, the governor ordered that the Troubleshooters be "the designated Protection and Advocacy Agency throughout the state for all persons with developmental disabilities and other handicaps." Today, the agencies are powered by $40,000 Protection and Advocacy funds, $440,000 CETA funding, $160,000 worth of Vista Volunteer service and $400,000 of "in kind" and other volunteer services from 45 agencies who have established formal and informal alliances.

All those preparing for Troubleshooter positions undergo a rigorous and relevant 30-day training experience. Throughout the month, the trainee lives with a handicapped person in order to gain first-hand experience with such an individual and with the problems he or she most face. The training program covers: the civil and human rights of handicapped persons; the unique needs of the person and his or her own family; the benefits and services available; and exhaustive skill training in how to secure services from every agency that is charged with the provision of such services. The program also includes sessions on the quick recognition of the various application forms and the rules that govern their completion. As part of their training, prospective Troubleshooters fill out the forms themselves. Monthly in-service training is conducted, providing added vitality to the agencies.

Troubleshooter offices often resemble the telephone "boiler room" in a political campaign, with two or three Troubleshooters manning phones which are in constant use. On a calm day in Seattle, a Troubleshooter will log about 20 calls. On busy days, there can be over 35 calls per person, with a grand total for the day exceeding 100. Thirty percent of the conversations have to do with carefully listening to problems and slowly going over a sequence of steps that need to be carried out by a family. Seventy percent of the calls deal with the office's efforts to follow applications, ask questions of agency officials and call attention to breakdowns in service systems. An active card file is kept on every family or client involved in a problem-solving situation with the Troubleshooters. The goal is to help the parent or client grow into "self advocacy." Said one Troubleshooter: "If we just solved the family's problems when they called, we would weaken them. Instead, we go over the steps of a situation, one by one, and we help them know what they need to do next. We even send texts of letters or checklists in the mail which they can use." Nevertheless, when it becomes evident that parents have done everything they can do, and the agency is still unresponsive, the Troubleshooters have strategies they take on behalf of the families. ("We even have a habit of calling the top official in an agency when we have to.")

To keep the public informed—and motivated—the Troubleshooters publish "The Inside Scoop," a monthly newsletter with a circulation of 12,000 which is sent through the mailing lists of many voluntary and professional agencies. The newsletter is playfully but seriously written, with an Ann Landers flair. It contains some of the previous month's actual pleas for help (the requester's identity is kept anonymous); each plea is answered with either specific advice or a review of how the problem was solved. The newsletter has also published "affirmative action statements" by agencies, specimen texts of letters to bureaus and simple explanations of current legislation, showing the weaknesses and strengths from the family's viewpoint. "The Inside Scoop" has proven to be interesting and helpful reading for parents, professionals, citizens and government officials throughout the state.

The activism of the Troubleshooters has generated a number of remarkable ideas, schemes and materials, many of which have found their way into other community operations. Some examples:

- *The no parent pay policy.* The Troubleshooters believe that assistance to families of developmentally disabled persons should be without charge—not even on a sliding scale. ("In our communities, fire assistance, police assistance, public school education, emergency medical assistance and many other services are already covered in our taxes. The parents of handicapped children are involved in a painful emergency they didn't ask for which should be covered in taxes, too. If they have to pay for these services, it amounts to double taxation.")
- *Medical Advocacy.* The Troubleshooters were instrumental in setting up a program to train and match medical, premedical and other preservice trainees with developmentally disabled persons who need advocacy during a period when they require health services. The organization is now independent and is based in one of Seattle's hospitals.
- *Community College Courses.* The enthusiasm of the Troubleshooters has been contagious. The curriculum of their rich, informational training program has been revised for use with parents and interested citizens who wish to take the course at many community colleges in the state.
- *Group Home Schemes.* The Troubleshooters have set up, and closely monitor, "instant group homes" and "cooperative rentals" for developmentally disabled persons on the basis of SSI payments and other support payments from state funds, without the need for any residential care agency intervention.
- *Creative Tension.* After gaining an understanding of both the Troubleshooters and the aforementioned Washington State Home-Aid Resources Program, it is possible to sense a creative tension between the two groups. The two agencies might not admit that they are good for each other, but they are. The state agency has power but so does the family advocacy agency, and it is this balance of power that has enabled the State of Washington to create services that go beyond the ordinary.

While one agency builds a program system and publicizes it from the government's point of view, the other watches its delivery to families and criticizes it from the consumer's perspective. The Troubleshooters know that if a service system, no matter how elaborate or well publicized it may be, does not reach and help the families for which it was intended, then *something is wrong with that system.* And the most helpful thing they can do is to publicly expose it at the point of breakdown. The Troubleshooters' unofficial motto puts it this way: *God helps those who help themselves. But the systems help those who know the systems.*

Public School Education

Friday
Saturday

A PUBLIC SCHOOL EDUCATION THAT BEGINS AT BIRTH

When children are developing normally, everyone remains calm. The parents surround them with a family structure, the physician checks them periodically and in due course the educators provide them with a public school education. Everyone watches quietly as the children develop on their own. But there is a growing urge within everyone to intervene *dramatically* when a child shows signs of retardation. Parents become concerned and look everywhere for help. Physicians do not say, "Bring him back in three months" or "Maybe she'll grow out of it"; instead, they consult other professionals and make the child the object of day-to-day observations.

Now that the public school education of retarded children is a fact of life, "everyone" includes teachers and school administrators, too. And, like so many professionals and parents, they have begun to realize that a handicapped child's education must begin early if it is to be effective. True, Public Law 94-142 calls for the education of the handicapped to begin at age three, but some educators are not even satisfied with that. They want to break through all school age admission rules, to work shoulder to shoulder with other pediatric professionals and to deliver training programs as close to birth as possible. When a child is found to be retarded, there is a growing urge in everyone to intervene dramatically . . . and to do it early.

Spring Harbor Elementary School, Madison, Wisconsin

In this community, any child from birth to five years who is handicapped or "at risk" can become a public school student immediately. There is no uncertainty about acceptance, nor is there any waiting until normal school age. A school district supervisor, for example, explained how little Amy was "enrolled" 25 minutes after she was born. As soon as Amy's pediatrician knew that she was handicapped he informed the father in the waiting room and explained how the local public schools had programs to help such children. Wasting no time, the father went to a pay telephone and called to get Amy "in school." This is only one of many incidents which demonstrate Madison Metropolitan School District's adamant determination to maintain "zero exclusion for handicapped children."

Spring Harbor School is one of three elementary schools, strategically located throughout the city, which provides early childhood educational instruction. There is no attempt, in any of the three schools, to conduct the programs "off to the side." Instead, the students, teachers and parents are accepted as an integral part of the schools' programs.

For younger infants, the school sends a special education teacher—called a parent advisor—into the home at regular intervals. There, parents are helped to develop training programs in the family setting. As the children gain in weight and strength, they are placed in one of five programs at the school. Once a child is in a school program, the parent advisor visits less in the home, but she never completely stops as long as the child is in the program.

At Spring Harbor, the classrooms—located in the middle of the building have brightly colored walls and rugs and an abundance of toys and play equipment. In this attractive setting, professionals, parents and elementary school students help 35 children overcome or compensate for such problems as hydrocephaly, Down's Syndrome, cerebral palsy, spina bifida, and the absence of speech, sight, hearing, arms or legs. Thirty percent of the children are severely and profoundly handicapped.

The activities in this school are constantly being evaluated and changed. One teacher gave this explanation:

> If you came back in a year, you'd see a different program. It has to be this way. We have only five precious years with a handicapped child before he's school age. We must not waste this time. All of us try to develop specific instructional activities that will enable each child to make kindergarten. That's a big jump for these kids, but some of them make it. For those who don't make it, we can document that they are many steps beyond where they would have been without this program.

The following are some of the components that are included in the early childhood program at this time:

- *Normal Preschoolers Integrated.* Ten normal preschool children are distributed throughout the five groups as regular members of the program. They receive individualized training like their handicapped classmates, but they also serve as peer models. Many parents of normal children in the community have requested this type of exposure for their children. Some want it simply for the preschool experience, while others want their children to develop skills in understanding and accepting handicapped persons. There is never a waiting list for handicapped students, but there is a long one for normal children.
- *Regular Students Involved.* There is a constant search for creative interactions that can take place between the handicapped children and the regular elementary students. Some regular students come to the

early childhood classes on special assignments to work as helpers and tutors. (Specific components on the individualized instruction plans are so exact that a regular student can be trained to carry them out.) Other students make casual visits. On special occasions, a regular class is invited to attend a party in the early childhood classrooms. At such times, the regular students are encouraged to be "receivers," since this helps the handicapped children understand that they can be "givers," too. One more attempt to ready these children for the "big step" into kindergarten comes when advanced handicapped students are scheduled into regular classes for specific periods such as socialization and music times.

- *Staff Flexibility.* The only full-time persons in the early childhood groups are the teacher and the teacher's aides. Regular students, speech and language technicians, an occupational therapist, in-home parent advisors and parents come for special involvements with the children and then leave. Other technicians from the medical, psychological and social disciplines are available as needed.
- *Options for Parents.* Since parents possess a wide range of talents and deficiencies, a number of options are available, enabling parents to choose how they would like to be involved. A university based advisor has identified 27 possible options. For example: carrying out specific data based instructional programs; observing sessions; conducting tours of the program; scheduling and participating in coffee meetings with other parents; sharing information with new parents whose child has a similar handicap; maintaining a daily communications notebook that goes back and forth with the child; serving on the school's regular and special advisory councils; helping with field trips; and teaming with a teacher for speaking engagements.

The parent is given the option to not be involved. In some circumstances this the most appropriate choice, but it seldom happens since parents usually want to do things they are capable of doing.

- *Individualized Programming in the Group.* The early childhood teams, being responsible for developing precise individual educational plans, demonstrate remarkable competency in analyzing behavior, developing sequential steps in a task, cueing, measuring change and reinforcing positive achievements.

The emphasis is very much on the practical, on teaching the handicapped children to be independent and self-sufficient. For example, they are taught to identify and utilize the many components of preparing snack time, rather than being given some artificial task like putting squares and triangles in their proper holes on a board. They are encouraged to complete tasks for themselves, without help from the staff, even if this means extra time and difficulty. And although the tasks are individualized, there are no one-to-one programs in the class—for the simple reason that there are no one-to-one programs in kindergarten, the next step for many of the children.

One result of this emphasis on the practical is that the children become "hardened" to their environment. They learn to overcome natural obstacles. A case in point: There are steps leading up to the classroom and the children learn to scoot, crawl or work themselves up to the top any way they can. Because the staff members regard this toughening process as highly valuable, they view with misgivings the fact that next year the classes must move to a "barrier free" school in accordance with Section 504 of the Federal Rehabilitation Act. Says one staff member: "We need those stairs for our kids. We'll find some stairs somewhere in the new school."

- *The Parent Advisor.* In many schools, the teacher who is the parent advisor would be called the "in-home trainer." At Spring Harbor, such a title presumes too much. The parent advisor explained:

> When I go into someone else's home, I am a guest. I have no right to push or hard sell anything in somebody else's home. And when we meet over a cup of coffee at the kitchen table, I stay open and alert for all kinds of things they want to do for their child.

The parent advisor is skilled in a wide range of educational and therapeutic interventions, so she listens and waits for the parents *to tell her* what skills they want to develop with their child. Although she refuses to be called a trainer, she ends up doing more training than many who carry the title.

As mentioned earlier, the Early Childhood Program must move from Spring Harbor School at the end of the 1977-78 school year to a "barrier free" school. It is a move that no one is looking forward to — neither teachers, parents nor regular students. The principal explained why:

> The Early Childhood Program came to us last September after a brief stay in temporary quarters. As soon as they arrived at Spring Harbor, they gave our staff a lift. We found them to be a super group of professionals, and all of us have grown tremendously because of their presence. Even I as the administrator have been richly influenced as well.

Although the early childhood staff have won the respect of those around them, they continue to be a driven group, searching for better interventions than those they now possess. Some even have the irrational belief that "we have failed every time a child doesn't make kindergarten." They know, of course, that many will not make it, but they continue to intervene at every point where a young child's intricately coded mechanism for early rapid growth seems to be tripping over itself. For them, the time is short and kindergarten age comes all too soon.

THE SCHOOL THAT HELD ITS OWN CHILDFIND

When Congress passed the Right to Education for All Handicapped Act, it was like throwing a very large rock in a pond. First the "splash" of the nearly unanimous vote (House of Representatives, 404 to 7; Senate, 87 to 7), then the "ripples," which traveled to every public school district in the nation.

But the new law called for changes, and changes in educational systems—or any system, for that matter—are often difficult to bring about. It is not just that people are forced to give up familiar practices; sometimes, new, completely unfamiliar practices are thrust upon them. When this happens, people are faced with a dual problem: first, they must overcome the natural resistance to giving up cherished ways; second, they must find solutions where there are no precedents.

One of the major changes forced upon school districts by P.L. 94-142 has to do with the locating of handicapped children. In the past, the schools simply waited for the children to arrive at the age of five or six. Now, schools must locate the handicapped children. More than that: Once the children are found, there must be a worthwhile educational program to help them.

Many school districts, by being ready for the changes, have been able to minimize the problems. One good example can be found in Bennington, Vermont.

Molly Stark Elementary School, Bennington, Vermont.

This small town school took P.L. 94-142 seriously. It conducted its own "childfind" and came up with seven severely and profoundly handicapped children (ages 7 to 10) in need of a public school education. The school already had classes for "trainable" and "educable" mentally retarded children, but not liking these labels, the classes were designated "Level I" and "Level II." A teacher was recruited from a local college and two teacher's aides were hired from the community. Staff members of the University of Vermont's Special Education Department were brought in as consultants. And seven children—who had never attended school before—began their education in September with the normal children in the neighborhood. Their class was called simply "The Early Learning Group." (The terms "severe" and "profound" were not liked either.)

When school opened in the fall, the seven came to school for the first time in their lives. Some could not walk; others had a faraway look in their eyes as if they were living in another world. One child rocked, slapped himself and made incoherent noises. The principal had this to say about those first days:

> How did we react at first? It was 'wow' for all of us. When we first saw them in the lunchroom, they seemed so frail. Some teachers were afraid they'd get run over. Then our custodian swung into action. He built a special platform so that some of them could sit at a lunch table like the rest. Other students began to help. Now, some regular students are assigned to work with them at mealtime.

By spring, the members of the class had developed such good eating skills and control that visitors could no longer identify them by their looks or behavior. One teacher, responding to such a lunchroom search, pointed them out and remarked humorously, "Now I suppose we ought to paint them green so they'll be easier to find."

One father told how he and his family had been forced to consider institutionalizing their ten-year-old daughter. He spoke of bad balance, three broken legs, aimless movements, periods of screaming and an unresponsiveness to everyone. "We could have done cartwheels and shot off firecrackers and Margie wouldn't have responded to us," he said.

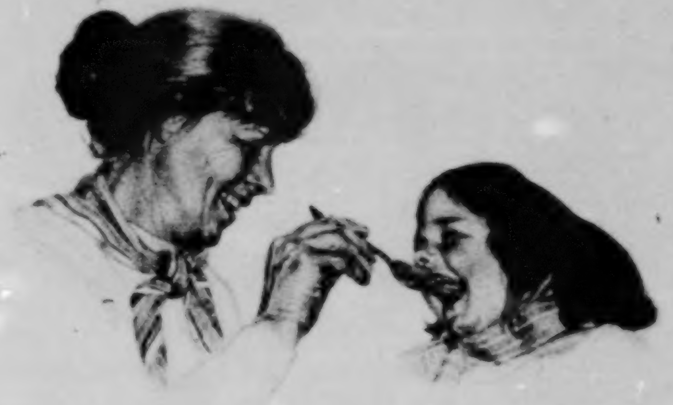
This family had been giving constant care to Margie, around-the-clock with no vacation for the past ten years. The father was frank: "Let's face it. We let her come to school because my wife needed a break. This school was our respite care."

In school, Margie became involved in 12 precise instructional programs. They focused on: attending, undressing skills (dressing skills come later), scooping with a spoon, drinking from a cup, washing hands in cold water (hot and cold water come later, too), toileting, object recognition, physical obstacles, natural gestures (gross hand sign language), grasping and releasing, toothbrushing and interacting with people.

Such skills are, of course, taken for granted in the development of a normal child. In Margie's case, however, the skills were dealt with one by one. Every positive response was recorded, along with data on whether Margie accomplished the task on her own, on cue, or with physical help.

Today, Margie's educational program is working. Her father spoke of how his daughter has changed:

> She can take her clothes off. Before, she couldn't relate at all, but now she's bubbly. She wants to kiss everyone. She's discovered television. She started with "Sesame Street" because, I think she identified with the children. Then she moved to game shows and now it's cartoons. She's able to signal when she wants the channel switched. Her communication has enlarged. We understand her repertoire and now she knows we understand. She's even competitive with her brothers and sisters . . . The school has been the greatest help for my wife. It's made our family strong. And when our family is stong, we can do more for Margie than the government or anybody else.



Helping handicapped children can be contagious. People volunteer their services to the Molly Stark Elementary School simply to help the seven children—and the others who will come after them—achieve a better life. For example:

When a mother saw achievements in her daughter, she became involved to the extent that she now works as an assistant to the regular PE teacher with the Early Learning Group. Together, the professional and the mother carry out PE activities that are both precise and measurable.

A regular student has been granted permission to work with her handicapped sister in the lunchroom. The student and her teacher now have lively conversations about what it means to have a handicapped sister. The handicapped girl responds strongly to her sister and their interaction carries over into the home.

Jonathan, a regular student, goes to the Early Learning Group every morning at eleven. He helps the class go to the lunchroom, get their trays, and he assists with their mealtime skills. The job has made Jonathan feel like a hero and his interest in school and in his own studies has improved.

The school custodian has become extremely interested in the children, helping them in the halls and lunchroom, and building special equipment the children needed. He says, "This is the best thing that has ever happened to this school. The regular children learn from the handicapped ones, and the handicapped children learn from the regular ones. Never before has this school been so rich and alive."

Members of the University of Vermont's Special Education Department come regularly to Molly Stark School to provide inservice training to regular and special teachers as well as to volunteers who are involved in the Early Learning Group. For example, the volunteer mother and the regular physical education teacher take one of the classes, while the head teacher—who is working on her master's degree—takes another.

The University's professors in the field of the severely and profoundly handicapped are vigorously committed to small teaching arrangements throughout the state. More than half of the preparation for teaching such handicapped children is connected with real classroom settings throughout Vermont.

In addition to the usual mainstreaming of lunchroom, halls and assemblies, the following activities are taking place:

- Some children from the Early Learning Group are assigned to the kindergarten during social language stimulation and peer interaction periods.
- The teacher of the Early Learning Group participates in the "teacher switch" and exchanges teaching duties with the teacher of a different class. Before the switch takes place, the two teachers meet and help each other prepare; after the exchange, they meet and share experiences.
- The special education teacher now serves on the Inter-school Support Team, a small select group of teachers who help other teachers cope with problem children.

Teaching handicapped children at Molly Stark—and keeping them home and out of institutions—makes financial sense. It has been estimated that it costs approximately $20,000 a year to institutionalize a child in Vermont; the people in Bennington serve the child for much less. However, the principal of the school makes it clear that money is not the biggest issue:

> The real key is an equal educational opportunity. I know it costs more than the regular children, and I know we don't have tons of money. But educators in this district intend to respond to every child's educational needs . . . Furthermore, we need to begin working with handicapped kids from birth. Everyone, from the superintendent on down, wants to meet the learning needs of these boys and girls.

THE EXODUS FROM BADGER TO GLENDALE SCHOOLS

For more years than we can remember, the education of mentally retarded persons has taken place in settings located apart from the regular schools. Segregated settings were established because most educators felt the regular schools were not suitable environments for mentally retarded persons. But times change, and regular schools are now inviting handicapped persons to attend classes in the same buildings as regular students.

After all these years of segregation, however, there is still a tendency to be fearful of such arrangements. It is not easy to leave a secure, familiar area and move into strange territory. Nor is it easy to adjust to strangers who move in as well. Such is the twofold predicament that many school districts will face in the near future. How will students in segregated special education buildings eventually be merged with those in regular school buildings?

Badger School and Glendale Elementary School, Madison Wisconsin.

One of the nation's most famous special education schools no longer exists. It was abandoned and left to slip into oblivion in the summer of 1977 when 32 severely and profoundly multihandicapped children, their teachers, therapists and equipment moved from Badger School to Glendale Elementary School. While the transfer was taking place, those who had become attached to Badger School shook their heads and wondered why it had to happen. After all, some of the most enlightened attitudes in regard to handicapped students—and some of the richest technologies for helping them—were shaped within Badger's halls, while educators from around the world came to observe and learn. Now some people were being forced to abandon what had become their Mecca.

Badger's history was short but rich. It opened in the fall of 1970 as the Madison Metropolitan Public School District's special education school. By 1973, there were 140 students with a wide range of handicapping conditions who travelled to its classes from all over the city. When the school developed MAZE (Madison's Alternative for Zero Exclusion) one year later, the Badger School became the center of a vigorous effort to *deny no child a public school education because of his or her handicap*.

Beginning in 1974, the first wave of handicapped students moved to regular schools when "trainable" students were transferred to elementary, middle and high schools throughout the district. In the spring of 1977, the MAZE program was terminated; Madison had made its point that no child, regardless of handicap, would be excluded from a public school. Only 46 multihandicapped students were left in the building. Many thought that these students should stay at Badger and that the building should remain open as a tribute to its accomplishments. But the deficiation of buildings and the needs of children are separate things, and so the administration ruled that Badger's usefulness had come to an end.

The sequence of events which took place during the exodus from Badger is every bit as valuable to the field of mental retardation as the school's accomplishments when it was thriving. The value lies in the smoothness with which school officials of both Badger and Glendale identified and dealt with the barriers hindering the transfer. The following chronological account may be of some help to special schools who are considering a transfer to regular schools in the future.

December, 1976: *The principals met with the superintendent*. Dr. Tim Crowner of Badger and Dr. Jerry Johnson of Glendale were called in to the superintendent's office to consider bringing the two student bodies together. It was suggested that 32 elementary age students could be transferred to Glendale, while 14 older students could go to secondary schools. Dr. Johnson's response was typical. What would happen to his program? Glendale already had an excellent program which mainstreamed hearing-impaired children in regular classes. Would he have to give it up? Also, he knew nothing about the children at Badger, so he asked for time to "process" the idea.

The Holiday Season 1976-77: *The principals began working closely together*. Shortly after their meeting with the superintendent, Dr. Crowner and Dr. Johnson met and attempted to gain an overview of all that was involved in such a move. Dr. Johnson wrote a series of seven alternative floor plans for Glendale which might accommodate both student bodies. (In a month, the seven would be narrowed to three.) Immediately after the first of the year, Dr. Johnson made his first tour of Badger School.

Early January, 1977: *The proposed merger was discussed at both schools*. Each principal passed the news to their faculties and parents.

At Glendale, Dr. Johnson first discussed the move with his cabinet of teacher and parent representatives. Three days later, it was presented to the entire staff, with more parents in attendance. This group voiced three major concerns: What would it be like to have more students in the school? Who would have to move to different classrooms? How would the presence of multihandicapped children affect the school?

At Badger, the greatest fears of the staff and parents had to do with the children. These handicapped boys and girls already had more than their share of rejection from people in the community. Would they receive even more from the non-handicapped schoolmates? How could all of their needs for special personnel and equipment be met in a regular school?

January 12: *The Glendale steering committee visited Badger*. A small group of responsible teachers and parents visited Badger School for the first time. On the way back to Glendale, there was silence in the car. Then a teacher asked the question that everyone was thinking: "Do you mean we are going to mainstream those kids?" Heretofore, the Glendale teachers and parents had not been aware of the severity of handicaps in the Badger children. Later, this same group began to think favorably about the merger; they could see that it would be a healthy challenge.

January 26: *The administration gave the "go ahead."* Everyone had been invited to express his or her fears about the merger and to consider its feasibility. By the latter days of January, many persons started to think the merger could work. Since time was short, and there was much work to do, the superintendent announced the move.

Public School Education

At this time, Dr. Crowner announced his future move to another assignment. Such a shift is customary when two schools merge, and he delegated Badger's leadership for the transfer to his administrative assistant, Mrs. Pat Van Deventer, who would be making the transfer with the children.

February: *A flurry of visits back and forth.* Many key individuals from both schools were detailed to visit the other school and gather specific data. For example, therapists from Badger went to Glendale to consider accessibility problems, bathroom needs and special areas of therapeutic equipment. Dr. Johnson and Mrs. Van Deventer met regularly—first at one school, then at the other. Dr. Johnson explained, "It was the only way I could get a 'handle' on the kids and their needs."

February 17-18: *The entire Badger staff visited Glendale.* They met with Dr. Johnson and toured the building. The teachers were given a chance to express their ideas about the move and suggest areas where their class would fit best at Glendale.

March 7-18: *Many small groups visited Badger.* During this two-week period, 22 groups of parents and teachers from Glendale toured the Badger School. They attended special presentations and were helped to get an understanding of the measurable growth that was taking place in the handicapped students. When the Glendale teachers and parents began to understand the developmental patterns that were being cued and reinforced in the children, they started to speak hopefully about the coming merger. ("I think our kids will get more from your kids." . . . "It looks like we have a lot of work to do together.")

April: *Numerous detail meetings were held.* The three alternative floor plans had been narrowed to one: The Badger students were to move into the east section of the first floor. The time had come to get down to planning and carrying out such specific details as bus access, ramping, widening classroom doors, constructing additional bathrooms, allocating space for therapeutic equipment and remodeling new classroom areas for the regular students. Dr. Johnson and Mrs. Van Deventer delegated detail work to every staff member in both schools.

May 2: *Glendale personnel began inservice training at Badger.* An all-day inservice training program on the education of severely and profoundly handicapped persons was scheduled for all Glendale staff members and some parents. The schedule included rationales and demonstrations of training techniques, videotaped records of measurable growth in the Badger children and slide presentations describing each classroom situation.

May 16: *Inservice training at Glendale for Badger personnel.* At this training session, special educators and parents of handicapped children learned about programs in a regular school. Interestingly enough, many of the special education teachers had never been exposed to regular education.

May 19: *Both schools attend a final meeting at Glendale.* This meeting, which took place a few days before the end of the 1976-77 school year, was the largest, most climactic meeting of all. Small groups were scattered everywhere to review and comment upon the complete plan. This was the opportunity—planned by Mrs. Van Deventer and Dr. Johnson—to get everybody to "process" the plan in their thinking one more time.

Summer: *The long-awaited move took place.* The heavy planning was over. Remodeling crews went into action and trucks began moving equipment and furniture from Badger to Glendale. By July 1, 1977, Badger School was an empty shell.

Fall: *The new school year began.* The opening of school was similar to other years, except that some children needed help finding their new classroom. The fact that the school now had six classes of severely and profoundly handicapped children was simply accepted.

In the first four weeks of school, no formal mention was made of the new schoolmates from Badger. During the fourth week, however, every regular teacher was teamed with two special education teachers to plan an inservice program on severe and profoundly handicapped children, each session was designed with the regular students in mind. Each class in the school received a program geared to its level. Regular students were helped to handle and operate special equipment, ride in wheelchairs, walk on crutches, balance blindfolded on a tilt board, role play critical situations, watch videotaped interventions and see audio-visual presentations on mental retardation. Older children were encouraged to write out specific questions requiring elaborate answers; some even wrote lengthy compositions on various aspects of being handicapped.

When the sessions were over, many things happened spontaneously. Some classes asked for follow-up sessions, while other classes invited the handicapped children to their rooms for parties. But most remarkable of all, individual students—during lunch break and recess—walked into the special education classes and asked if they could help.

Looking back on the merger, one can only say that it happened—without fanfare and without special assemblies to prepare the students. For the most part, the students were already prepared. But why wasn't there more resistance? (The principal did not receive one negative phone call.) The answer can be found on three levels:

- The district administrators made a crucial, forward-looking decision that reflected the most advanced trends.
- Two leaders possessed the ability to draw up a plan which allowed people to speak their minds repeatedly and "process" their thinking.
- That staff and parents of the two schools were able to counsel and train each other—over and over until all the myths and fears had fallen away. This was the most powerful strength of all.

THE IMMENSE JOURNEY: FROM BASEMENT TO CLASSROOM

In a guest editorial in the "Pottstown Mercury" (January 23, 1976), James Hirst, the father of a retarded son, called for the inclusion of handicapped children in the public schools. The editorial drew some negative letters to the editor. One woman who signed herself "Skeptic" said, "I thought it was a wonderful idea, but it's a shame it won't work in our society today. Children can be cruel . . ." She then described some of the destructive myths that grow like weeds in our society.

Today, as extraordinary efforts are being exerted to heal the breach between the mentally retarded and the so-called normal persons in our nation, such myths must be dealt with one by one. This is no easy task. A society does not surrender its myths easily.

Owen J. Roberts Middle School Pottstown, Pa.

Today, a class of "trainable" mentally retarded students—11 of them—attend classes in this regular school building, located in the rural countryside outside of Pottstown. With the regular students, they ride the school bus, eat in the lunchroom, attend assemblies and enjoy all the general rights and privileges of this middle school.

In addition to specialized programs in their own classrooms, they attend special courses with regular teachers in gym, art, music, home economics, industrial arts and swimming. Regular students spend periods in the special class as teaching "advocates," assisting handicapped students with such tasks as counting money, sorting, telling time, measuring and using a calculator. The advocates became involved after responding to one of the all-school requests for volunteers. Although 70 to 100 volunteer each semester, only 10 to 15 can be used efficiently each week. These advocacy relationships have remarkable carryover into the halls, lunchrooms and playgrounds, where friendly greetings and conversations between handicapped and non-handicapped students are numerous. None of the predictions that regular students would inflict cruelty and ridicule on the handicapped children have materialized.

The special class—now accepted as a natural part of the student body—came into being after a long, hard struggle by a few families, the responsiveness of Chester County Intermediate Unit #24 (which is administratively responsible for such classes) and the willingness of the Owen J. Roberts School District to work with handicapped persons.

It is common knowledge that parent concern and pressure have impacted creatively on the education of handicapped persons, but few have so thoughtfully documented their struggles and successes as precisely as one family in Chester County. Consequently, their efforts stand out vividly in this description.

The family has twin sons, 14 years of age, who now attend Owen J. Roberts School. Sam is in the school's program for the gifted, while Jim, a victim of Down's Syndrome, is in the special class. When they were five years old, Sam was admitted to kindergarten, but Jim was sent to a nursery for a few hours each day. Thus began a series of inequities in their education that lasted for seven years. Sam moved up the educational ladder with ease; Jim's ladder became an obstacle course. His journey—which started late—looked like this.

- At eight years, Jim began attending a segregated special education school at Coatesville which was operated by the Intermediate Unit (IU). His travel time to and from school was over an hour each way.
- At 10, he attended a school operated by the IU in a Phoenixville church basement.
- The next two years were spent in an IU-operated church basement in Spring City.

In all of this time, the parents were painfully aware of the differences in the amount and quality of education their sons received. Jim always seemed to be traveling farther and getting less. In the last church basement, there were three special classes, no playground and a catered lunch that, according to reports, usually consisted of soup and sandwiches. Sam, on the other hand, travelled a few minutes from home to a regular school where he received a "full service" education.

Year after year, the parents wrote to and met with government officials trying to correct the "blatantly unfair" discrepancies between Sam's and Jim's educational opportunities. They were received politely, but little was done. Then, in January, 1975, the parents wrote "A Proposal for a Mainstreaming and Normalization Program for Mentally Handicapped Students in Chester County." The proposal was sent to key state officials and was circulated locally as well. The document contained the following details:

- A detailed list of the educational components Sam received in the regular school.
- A detailed list of the same components which Jim did not receive. Some examples: a full range of programs, a safe and stimulating environment, sufficient staff, equipment and materials, a full range physical education program, a school nurse, a rich offering of general all-school assemblies, rallies, sporting events and cultural arts and activities.
- An eight-point program for the development of "a model antisegregation and tactful but escalating" program of mainstreaming activities.
- Functional definitions of "mainstreaming," "normalization" and dehumanization."
- An added definition showing how the county historically engaged in the practice of "educational grouping by defect."
- A series of to-the-point quotations by nationally recognized experts.
- An appendix of newspaper clip

pings documenting that the public schools in the area had many empty seats (18,000, according to one survey).

- An appendix of in-school and extra curricular educational offerings available to all Owen J. Roberts students.

The parents gathered confidence from the data they had compiled and began discussions with an attorney. In a low-key way, they made it clear that they were willing to test their data in a court of law.

Simultaneously, the IU had been hard at work renting space in public schools and placing some of their special classes in them. There were many obstacles to be overcome. For example, some parents were petrified at the thought of having their handicapped child in a regular school; others feared their children would be victims of an overwhelming prejudice. Unlike the parents of Jim and Sam, these parents worked hard to block the transfers.

By spring, 1975, it was decided that the nomadic special class which Jim attended could make its home in the Owen J. Roberts District. However, when the decision was discussed with some parents of the class and other interested citizens, some understandable apprehensions were voiced. Most of them centered on the fear that regular students would be cruel and ridicule the retarded students. After thorough discussion, it was decided to go through with the merger. By that time it was summer. Everyone waited with a mingling of hope and fear for the coming school year.

In September, the class moved into the District System. The children spent their first year at the Vincent Elementary School, where none of the parents' fears materialized. Then, because they were growing, the youngsters were transferred to the middle school.

Many parents of the handicapped are active in the regular parent organization of the school. The principal has an open coffee hour for all parents once a week. According to him:

> All of our apprehensions about them didn't happen. Instead, the regular students are better because the handicapped are here. The warmth of the special class has permeated the whole building. And best of all, I haven't heard one regular student speak disparagingly or make fun of a handicapped student.

The teacher of the special class, who had been with the students since the days of the church basement, had developed a closeness with them and had demonstrated a remarkable competency in documenting each student's individual growth. He described the changes he saw in his students as a result of the merger:

> They show so much more vitality here with the regular students. When I watch them interact with the other students on the playground, in the lunchroom and in the halls, I can see it has been like a shot in the arm to them. It has been a beautiful experience.

Jim's twin brother, Sam, who is now involved in the "academically talented program" and doing independent research in astronomy, probably has the sharpest insights as to how his brother now functions:

> It's great! Jim and I ride the bus together to the school now, and his improvements are tremendous. His speech has improved dramatically. His behavior is so much better. Now, on our days off, we go to the mall and shop together, and all kinds of kids are walking up to say "Hi" to Jim and visit with him. They are all kids he got to know at school. Believe me, it's so much better than the days when he attended school in a church basement.

Recently, the parents of Jim and Sam did an interesting thing. They sent a letter to the school officials, thanking them for making it possible for Sam and Jim to be together in the same school district. In that letter, they made a detailed list of 17 educational experiences that Jim *now had,* which he never had before.

COMMUNITY REFERENCED EDUCATION

As a child without sight or hearing, Helen Keller, suddenly one day ran from object to object, and—with tears of joy in her eyes—she called each one by its name. Although mentally retarded persons may not react as dramatically, the richness of their lives—and sometimes their survival—depends on connecting what they learn in the classroom with everyday objects and events in the community.

La Follette High School, Madison, Wisconsin.

For a group of teenagers having both hearing impairments and mental retardation, education within the walls of a classroom was not enough. Consequently, the community had become their classroom, too. They, and their teachers, are learning that the town is alive with things which, when experienced in conjunction with their school lessons, enable them to function on their own, with greater skills and confidence, in the real world.

Although the teenagers' program has a high degree of relevancy and practicality, the teacher of the class made it clear that ". . . a program like this must have a high staff ratio, and the school must be close to many stores." La Follette High meets these requirements. For four multihandicapped students (ages 15 to 17), there is a teacher, a teacher's assistant, volunteers from the university and a number of regular high school students who serve as individual tutors receiving credit from the school's independent study department.

In the vicinity of the school, there are many stores and facilities that are part of their training forays. For example, the students carry out sequential training forays at: Donut Land, McDonalds, the Post Office, a small grocery store, variety store, hardware store, bicycle shop, paint store, bowling center, clothing store, handicraft shops, supermarket and drug store. As their competency increases, they also travel by bus to the city library and large shopping malls.

In class, all students work to develop competency in "total communication" (hand signs and voice), but they resort to a special notebook system for communicating with people in the community. The notebook contains a number of message pages, each encased in plastic, which are individualized to the student's level of functioning in various community settings. On a specific day, 16-year-old Larry's notebook contained the following messages:

Page 1: An identification page (including Larry's name, address, phone number and who to contact if lost.)

Page 2: "I am hearing impaired. I will show you a note."

Page 3: "I want to buy . . ." (A list of items can be slipped underneath the plastic. At the present time, they are pictures. Later, key words can be used as Larry learns to identify them.)

Page 4: A communication page with messages for the postal clerk.

Page 5: A communication page for buying lunch at McDonald's. (It includes the regular checklist used by counter employees and also pictures of mustard and ketchup).

Page 6: A page for getting photographs developed. (Larry takes many pictures in his educational program.)

Page 7: A page for buying film.

Page 8: A page for buying flash-bulbs.

Page 9: A page requesting help in tieing his shoes. (Larry also has cerebral palsy problems.)

The notebook is constantly revised as Larry's competencies and needs change. This ingenious communication device has helped students move competently throughout the community and to make decisions they have never made before. The student first goes into a setting with his notebook accompanied by a teacher or tutor. Then, as the student develops, the presence of the tutor is phased out until finally the student and his notebook move into the community alone.

Each student's community assignments are carefully written into a sequence of steps that are tailormade for that girl or boy. Seventeen-year-old Margaret, for example, now has the following steps dealing with shopping in a grocery store. Margaret will: (1) walk to the store; (2) select purchases; (3) check them off her list; (4) stand in line; (5) pay money; (6) receive change; (7) accept purchases; and (8) walk to the class. Each step is watched closely until Margaret can do them independently. With George, a 15-year-old, this particular task was broken into a series of smaller tasks of approximately eight steps each, since he is not as proficient as Margaret.

The noteworthy thing about Margaret's and George's shopping objectives is that they serve as an excellent educational program for carrying out what educators call "sequencing events in time," "tallying," "counting," "directioning," "developing spatial skills" and others that can be dealt with individually or in groups as necessary.

No task in the community is undertaken without a personalized, detailed checklist of behaviors. There are others having to do with crossing streets, observing traffic signals, finding directions, and using the laundromat, to name but a few of hundreds of tasks.

"The whole neighborhood has become our classroom," says the teacher's assistant. (She is in charge of the in-the-community activities, while the teacher handles the in-class academics derived from these experiences.) "Wherever we go, we find a new learning task that can be detailed and carried out step by step. Some of the students even go to an apartment and take training in how to keep it clean."

How have the students been received by the community? "Simply great," the teacher says. "We should build monuments for those people out there. Take McDonald's, for example. Those people are beautiful. They know our kids, they understand what they are trying to do and they have patiently worked to understand them."

When Terry went alone with his notebook to the hardware store, his note on the I-want-to-buy-page—his first scrawled attempt— said "Key Lockers." The salesman understood that Terry wanted to buy a lock for his locker and the purchase was made.

The teacher, reflecting on that event, commented, "You know, that was our class's first written communication to the outside world." Since then, there have been many more, and this practical, detailed educational tactic called "community referenced education" has made them possible.

THE TEAMING OF REGULAR AND SPECIAL TEACHERS

All too often, there is a wide gulf separating the regular classroom teacher and the special education teacher. One regular teacher in a public school on the West Coast put it this way: "We don't have much in common. The special teachers have a different type of training, and they do things differently. They work with small groups of six or eight, while my class has 28 students." A special teacher from the same school agreed. She felt that she was treated cordially, "but somehow I don't feel that I and my class have been fully accepted in this school."

The separation in this school is more real than imagined. Almost all activities of the special classes are carried out in their own area. The children come to school and leave at a different time. They study and eat lunch in their own groups. Nevertheless, the two special classes in this school were seen as a crowning achievement by the local association for retarded citizens and by a local university professor of special education who rated their IEP's (Individual Education Plans) as among the best in the nation. In spite of many interviews that elicited cutting edge ideas being used in the class, the longer one listened, the more one was struck by the apartness in this school. It is a far cry from what is happening in Madison, Wisconsin.

East High School, Madison, Wisconsin.

> The wall is coming down between regular and special teachers here at East High. On second thought, there are *two* walls that are collapsing, since each side had built up its own defenses. The thing that made it really happen here stems largely from our policy to put special and regular teachers together in team teaching programs whenever possible.

So spoke the assistant principal, who, along with his many other duties, is in charge of the special education efforts in this large urban high school (population: 2400 regular and 160 special students). Although the school has a long history of successful integration of handicapped and regular students in the halls, lunchrooms, assemblies, athletic events and general student privileges, the school has recently instituted other impressive features:

- The first 4-H organization for handicapped students in the state operates at East High.
- "The Learning Shop," a volunteer tutoring organization of regular students, takes assignments with mentally retarded students.
- "Drop In Night," a recreation program taking place one evening a week, encourages the participation of handicapped students.
- A sizeable, community-referenced, on-the-job training program places handicapped students and supervises periods of labor at work stations throughout the town. Seventy-five percent of these jobs are employer paid. Some examples: The Department of Public Instruction (filing and library aide work); a building maintenance corporation (custodial services for office, apartment and commercial buildings, as well as landscape services); a restaurant chain (washing dishes and busboy work); day care centers (child care aides); a bank (shredding records), a motel (room cleaning); and the Red Cross (collating, labeling, stapling).

There are key components that receive special attention when a team teaching program is undertaken. They are:

- A regular and special teacher are carefully matched. In the words of one teacher, "It's almost like a marriage. They have to get along together or everything is lost."
- A creative interchange of knowledge and skills must take place.
- Both teachers must undergo intensive inservice training programs.
- Instructional program plans are worked out together and specific responsibilities are assigned.
- The team must develop an evaluation procedure. This procedure not only measures how far each student has come; it serves as the groundwork for next year's course offerings as well.

The team is expected to conduct a basic course for handicapped students for one year. By then, some students have developed sufficiently to be tried in a regular course, with the regular teacher in charge and the special teacher dropping in as an advisor; other students may need to study in a special class led by the special teacher, with the regular teacher serving as a resource person.

Today, at East High, there are team teaching arrangements in physical education, agriculture, art, home economics, business and industrial arts. Plans are now underway for courses in horticulture.

This coming together of teachers has richly influenced both members of the team. A special education teacher described the feelings that each has developed for the other:

> I find the regular teachers have come to respect and admire me for what I can do. They understand why a special education class must have a richer teacher-to-student ratio. Now they say, "I don't know how you do it." On the other hand, I am impressed with the wide grasp of knowledge that a regular teacher can bring to a subject. I'm learning as much from them as my students are."

At East High, the differences between special and regular teachers have not been seen as an excuse for polite separation. Instead, it has become an opportunity for the creative development of a richer curriculum for all students. Special and regular teachers are no longer treated as two separate camps; rather, they represent a powerful, single, highly expanded program. Does this unique kind of team teaching work? The assistant principal says it does and—better than that—he feels it is "one more key to making today's educational desert bloom."

MENTALLY RETARDED PERSONS GO TO COLLEGE

By 1980, all 50 states will require the public education of mentally retarded persons until the age of 21. This cutoff point would be fair enough were we dealing with normal human beings. However, when applied to mentally retarded students, it is little short of tragic. Many handicapped persons are in the middle of the richest learning processes of their lives when "graduation" comes and the strengthening and liberating force of special education is abruptly stopped.

But need it stop? Should the end of public education mean the end of the retarded person's development. After all, many normal young men and women go on to college, so why can't the retarded go, too?

Denver, Colorado.

Severely handicapped persons are walking the campus of this four-year college as students. They carry college I.D. cards, attend school functions such as dances, rallies and the college movie series, and have regular access to the library and physical education facilities. They take courses, too. Not courses like Sociology 10B or Engineering Problems 2C, but such courses as General Experience Course (for students with deep handicapping conditions), Money Management, Riding the Bus, Assertiveness Training, Getting Along with Others, Symphony Appreciation, Keeping Healthy, Human Sexuality, Dating, Creative Cooking, Camping and Whitewater River Rafting. The list of courses is subject to yearly change, since it is based on what the students say they want to learn at a previous registration.

The department responsible for these courses is called the College for Living. Its birth took place when four problems were harnessed into a single solution:

- Denver had many mentally retarded adults whose quality of living was bleak.
- Some students were pleading for on-the-line training experiences.
- Some professors longed to tackle the practical problems along with the usual theoretical ones.
- Already paid-for classroom facilities were not being utilized during certain hours.

Little money is involved in the program, but everyone earns dividends of one sort or another. Regular college students become the teachers and receive college credit for doing so. The professors find that their teaching takes on new energy and relevancy. And the mentally retarded adults, who receive the biggest dividend of all, are committed to specific learning tasks and realize the joy of doing things they have never done before.

Teacher preparation begins when college students respond to publicity campaigns and attend screening interviews. If accepted, they enroll in a five-day orientation course (one credit) which includes: sessions on attitudes towards handicapped persons; panels of mentally retarded adults discussing their hopes and concerns; programs on teaching techniques; skill training in testing, evaluating and measuring the success of students; and tours of such facilities as nursing homes, institutions and community based services. The orientation is intense and most trainees emerge with far more enlightened views about handicapped persons.

The handicapped students register for courses just as all college students do. Some pay fees and some receive "scholarships." However, each student tells his or her registration counselor what he or she wants to learn in the future. These suggestions are reflected in the course offerings next semester. For example, some of the students were aware of "whitewater rafting," a popular sport on Colorado's mountain rivers. They requested a training course on the subject. The next semester, Whitewater River Rafting was on the course list.

Classes are conducted with a four-to-one or five-to-one student-to-teacher relationship. All are individualized instruction programs.

On the first class day, each student negotiates his or her own learning contract. For example, a student in money management chooses specific tasks he or she wants to undertake, from a wide range of possibilities: counting money, writing checks, weekly savings, keeping track of expenses and survival math. If a student has any other money management topics he'd like to work on, chances are the college will be able to accommodate him.

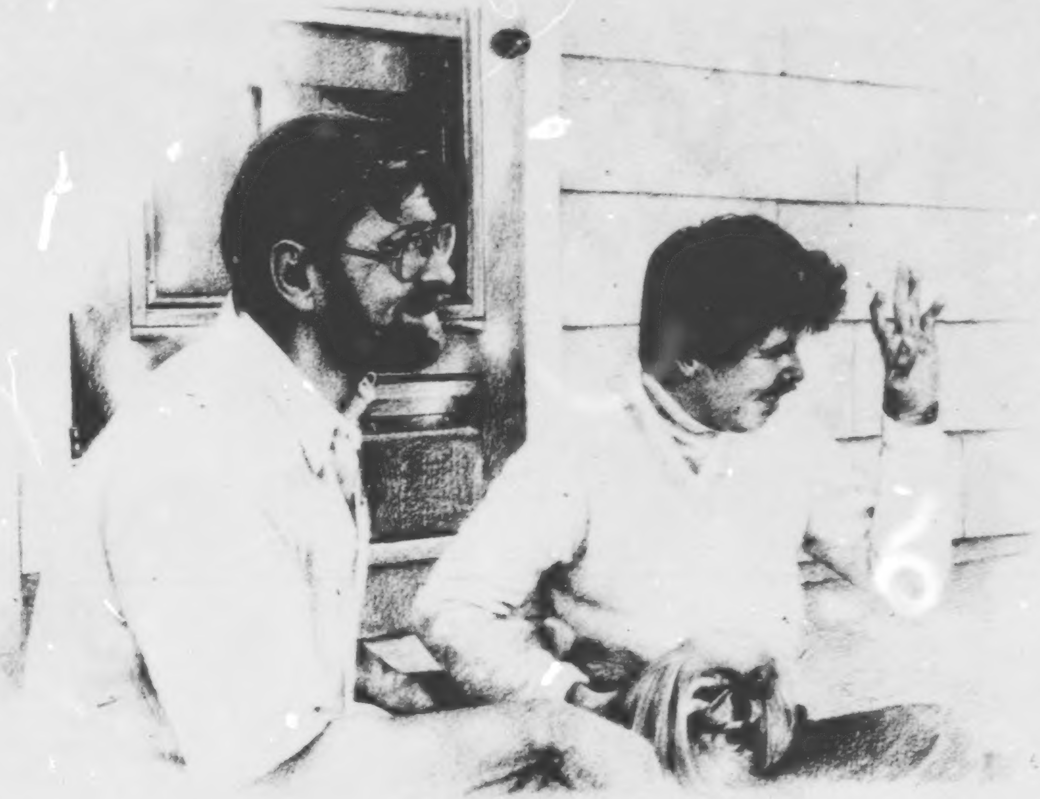
Goals are written down. Both teacher and student keep a copy. Midway in the semester, the goals are discussed and modified as necessary. At the end of the semester, the goals are reviewed. When the semester ends, the students, attend a special recognition night and receive certificates of achievement. Often, the president of Metropolitan State College participates in the ceremony.

In less than four years, Metropolitan State's College for Living has expanded enormously. In September, 1974, the program began with five teachers, 21 mentally retarded students and a $600 budget. By Spring, 1976, there were 40 teachers and 200 students. The program has been replicated at the University of Colorado at Boulder, Mesa College at Grand Junction, the University of Southern Colorado at Pueblo. All told, there are today 842 students and 206 teachers on 11 college and university campuses in Colorado.

The expansion has even moved beyond the state's borders. Programs can now be found at: The College of Staten Island, Staten Island, New York; Northern Virginia Community College, Annandale, Virginia; Mesa Community College, Mesa, Arizona; and Prairie Development Center, Atwood, Kansas. The trend continues at a rapid rate, and there is no sign of it slowing down.

See page 75 for photographs taken at Metropolitan State College.

Community Residences



IN OUR NEIGHBORHOOD, YES!

For years, people living on ordinary streets in ordinary communities had been led to believe that anyone who was mentally retarded should be sent away. The belief seemed right because most of the community's religious, therapeutic, legal and social spokesmen said it was right. Then, not too long ago, some citizens became convinced that sending retarded persons away was wrong, and they called for the return of handicapped people to the community. But others responded: *not in my neighborhood you don't!*

Such a reaction is, unfortunately, only to be expected. Many people do not cast off easily the beliefs inherited from previous, less enlightened generations. Try to change their minds and, more often than not, you earn only their wrath in return.

However, there *are* enlightened communities in the nation. In these communities live people who have organized themselves for the purpose of continually casting fresh light on neighborhood practices and beliefs. The communities are not perfect, of course, but with the enlightenment they gain, destructive beliefs are diminished and strides are being made toward attaining what is fair and just for everyone in the neighborhood, including mentally retarded persons. Hopefully, the gains these organized communities have made will help light the path for other neighborhoods which are also struggling to move out of the dark ages, too.

Philadelphia, Pennsylvania.

A community of 35,000 people in northwest Philadelphia, an area that is approximately 12 city blocks wide and 20 blocks long, has organized itself and has begun to take control of its own destiny. The neighborhood is racially integrated and the residents are drawn together by an active, grassroots community organization known as the East Mount Airy Neighbors, Inc. (EMAN). The ability of the residents to organize and carry out neighborhood tasks gives them a functioning identity that is unique in the City of Philadelphia.

For example: EMAN, with its 1600 paid members, its board of 36 representatives and six officers, operates a day care center, a community center and skill center for teenagers. It administers a block organization plan which carries out low profile safety and communications programs which require neither weapons nor CB radios. It organizes an annual community fair, campaigns against graffiti and enlists volunteers to beautify the landscape.

Small wonder, then, that when the State of Pennsylvania advertised for community homes for mentally retarded persons coming out of institutions, EMAN was one of the first organizations to respond.

Today, four group homes—three for adults and one for adolescents—are located in separate locations in the neighborhood. Each home houses six mentally retarded persons who live—at least as far as casual passers-by can see—pretty much as other people live. Outside, the homes are similar to the other residences on the block. Inside, the decorations are bright and tasteful, the furniture new and comfortable. Each of the four homes is not only a nice place to visit, but a nice place to live, too.

The program is built according to the highest principles of normalization, with residents being trained to live independently in the community. They learn to cook, do their own laundry and do everyday household tasks. During the day, they either work at their jobs or are in full-time training for a job. Evenings, weekends and holidays are busier than in most residential programs, with many opportunities for adult education and recreation.

Since some residents have progressed to the point where they are ready to live in a less restrictive setting, EMAN is developing four apartment programs which will be dispersed throughout the community. Two graduates of the group homes will move into each apartment and live semi-independently. The next step will be for the residents to find their own living quarters, with the staff gradually offering less and less support.

The administration of EMAN'S residential services is simple and highly efficient. There is an executive director and an administrative assistant. All other staff members are involved in direct care, including two full-time and two part-time employees in each home. Funding is provided by the state's Community Living Arrangement (CLA) program. The present budget is $280,000, which breaks down to approximately $11,600 per person each year. (Although an exact comparison cannot be easily arrived at, due to other factors involved, the yearly cost is $23,000 per person at the nearby institution where some of the group home residents once lived.) The annual budget for the apartment program will be $60,000, reducing the cost to $7500 each time a handicapped person moves into an apartment.

Although more could be said about the technology of the program, its most significant cutting edges lie in the following organizational strategies:

- *The program was initiated by the community.* This is not a case of impersonal state officials and community agents attempting to impose community living for retarded citizens on a neighborhood. It was the community's choice entirely.
- *The planning and development were deliberately kept low profile.* No press releases were sent to newspapers, announcing the opening of the group homes, as some agencies have done. Since that sort of thing is not done when other persons move into a home, why do it when retarded persons move in? There was even a low key, door-to-door discussion

campaign with the neighbors surrounding the home earmarked for purchase. In one block, there were neighbors who reacted negatively; that home was quietly dropped from the list of possibilities.

- *No attempts were made to compete with existing agencies.* EMAN made it clear that it was only interested in tapping its own neighborhood's potential for rendering human services to others. The local group admitted its amateur standing in the midst of so many professionals with years of technical training, and felt that competition would be foolish.
- *The program offers few "tourist attractions."* EMAN helps us all to see that the more normalizing and—to coin a new phrase for the field—the more "neighborly" a program is, the less there will be for mental retardation service "tourists" to see. There are no buildings named after trees, heavenly places or dead professionals; no commemorative plaques; and no innovative architecture and equipment. Instead, a visitor will find ordinary people, living in ordinary homes and doing the ordinary things that everyone else does. It is worth noting, by the way, that those individuals who entered the group homes from institutions looked much more retarded when they came than they do now.
- *Mental retardation becomes a community problem.* For years, the tendency has been for communities to pass off most of the responsibilities for the care and training of mentally retarded persons as problems for the state to handle. EMAN chose to accept all the responsibilities itself, believing as it did that the problems of integrating mentally retarded persons into a community can usually be solved more efficiently at the local level.

The EMAN group home program is a pioneering approach, and one wonders how this community took a problem that has been so complex nationally and managed to make it appear so simple. One clue can, perhaps, be found in the EMAN motto: *Help make a good community better.* Another clue is provided by Dennis Johnson, chairman of the group home board, in his description of EMAN as "an attempt to help everyone get along with each other, and to develop human service assistance as a byproduct."

Still another clue can be found in the words of Eversley Vaughan, a respected community leader, who wrote in a 1973 newsletter: "Something exciting is happening in EMAN—we have discovered each other and have declared ourselves to be interdependent." From these clues, we can begin to see that the secret of EMAN's success does not lie primarily in the training skills and program technology, as outstanding as they may be. Rather, it lies in the *attitudes* of the neighborhood.

THE RESIDENTIAL CLUSTERS OF EASTERN NEBRASKA

Not long ago, the delivery of residential services to mentally retarded citizens was organized by states in a very simple way. All resources were channeled to "total" institutions. Every dollar and every service activity was administered by a single agency which was responsible for all the needs of the handicapped resident.

It will never be that simple again. Indeed, the delivery of residential services to retarded persons in their own neighborhood will be an extremely complicated task, requiring more agencies, people and funding than ever before. Although many regions in the nation have begun to build such systems of residential services, no one has as yet completed the task, and no one knows what final shape such organizations will take.

Eastern Nebraska Community Office of Retardation, Omaha, Nebraska

On July 1, 1968, the Greater Omaha Association for Retarded Citizens presented the Douglas County Board with a plan which (1) described all components needed in a system of community based services for mentally retarded persons and (2) called for the return of all handicapped persons from the county who resided in Beatrice State Home, 90 miles away. The plan was approved. A few months later, neighboring Cass, Dodge, Sarpy and Washington Counties joined to make it a five-county effort, and one of the nation's most ambitious deinstitutionalization programs was underway.

The five-county program took place simultaneously with a larger state effort. In 1967, the governor appointed a Citizen's Study Committee on Mental Retardation, authorizing the committee members to survey and report on the human situations of retarded citizens throughout the state. That report was submitted to the governor on the same day that the Omaha group presented its plan to the Douglas County Board.

The state report documented that Nebraska was one of the least progressive states in the nation with regard to planning and funding for mental retardation services. Conditions at Beatrice State Home, the state's single large institution for mentally retarded persons, were grim. It was located in a remote, rural section of the state; it contained 2300 handicapped citizens who were forced to live in deplorable, overcrowded conditions; and the cost per resident was a mere $3.58 per day. At the same time, there were virtually no community services for mentally retarded persons in the state. This report received massive publicity which reached almost everyone from the citizen on the street to the governor himself.

By 1969, a total of 14 state laws were passed with mandates ranging from the organization of the state into six powerful community based service regions, to the repeal of a law ordering institutionalized females to be sterilized before moving back into the community.

It was with this added impetus that the five counties in Eastern Nebraska, comprising one-third of the state's 1.5 million population, were formed into Region VI, the Eastern Nebraska Community Office of Retardation (ENCOR). ENCOR began immediately to develop community service thrusts. The following is a description of the residential component of this regional service system as it exists today:

- *Support the Home First.* Through the years, ENCOR's policy has been to do everything possible to help the mentally retarded persons live at home before offering them residential care in the community. All ENCOR divisions join with many generic agencies to provide services which support mentally retarded persons in their own home. For adults, "home" means their natural setting in the community; and for children, it is with their family.
- *Residential Clusters.* Today, handicapped clients who have come from the institution or who can no longer be supported in their own home, live in one of 17 clustered subsystems of residences, where they are being helped to move through less and less restrictive settings and to take on more and more personal responsibilities as they develop. As clients become more responsible, they have increasingly less need for ENCOR services. To carry out this developmental process, each cluster is organized with one core residence and from 12 to 15 alternative living units (ALU's) around it.
- *Core Residences.* A core residence is a group home of not more than six recently admitted handicapped clients who live there for an average of from three to six months in order to "settle in." Here, the first individualized program plan (IPP) is developed by an interdisciplinary team consisting of the necessary ENCOR staff and other agency consultants, as well as the client and a family member or guardian. This first IPP is launched shortly after the client enters the core residence; it provides the initial data on an individual's growth pattern.

The recent admission of Mary Ann, a 43-year-old former resident of the institution, provides an example of ENCOR's initial program planning. She is learning to travel into the surrounding community, to use the telephone, to speak more clearly (teeth and jaw formation are being evaluated for possible surgical corrections simultaneously with initial speech training), to work daily in an industrial training center, to achieve a ser[illegible] of beginning industrial skills and to take part in various recreational opportunities. Also, Mary Ann is learning to maintain her own bedroom, carry out other specific housekeeping tasks and adopt acceptable behavior patterns.

As these initial tasks are accomplished, Mary Ann's personal growth pattern will become more apparent and predictable and an alternative living unit fitting her needs will be sought. Central to this developmental pattern is the core residence, the supervising "mother house" for the ALU's it develops.

- *Alternative Living Units.* It is the responsibility of the staff assigned to

Community Residences

Mary Ann's core residence to find an ALU in the community that meets her developmental needs and to change the ALU when her continued progress warrants it.

The numerous ALU's that now operate in the ENCOR system are, of course, as individual as the clients serviced by the system. An ALU can house from one to four handicapped clients; be in a city, a small town or on a farm; require 24 hours of intensive supervision or only three hours a week for assistance with shopping and checkbook balancing. Some clients live with a family in the community; others live alone in an apartment. Some may require only short-term crisis assistance, while others need long-term intensive training. As one ENCOR spokesman put it: "An ALU is any residence a particular person needs." All of the details are determined by the ever-changing IPP.

Many changes have taken place since the day the state report and county plan were submitted. Beatrice State Home has been renamed Beatrice State Developmental Center and its population has been reduced from 2300 to 850. All but 250 of an original 780 institutionalized citizens from Region VI have returned to the community—to independent living, their family homes, nursing homes or ENCOR residential settings (where 250 persons are accommodated in the 17 core residences or 105 ALU's throughout the five-county region). It has been estimated that more than 350 mentally retarded citizens in the region have been helped to stay in their homes instead of being sent to the institution, as would have been the case ten years ago.

Despite the many changes, all persons interviewed regarding the region's residential services still hold to the original, unifying goal of the 1968 Douglas County report: ". . . all will be returned to the county (now five counties) for care, education and training." As the effort continues, ENCOR is attempting to solve the following problems:

- *Severity of Handicap.* Of the 250 persons still at the institution, 60 percent are severely and profoundly handicapped. As a result, the agency must develop a more intensified technology than ever before.
- *Nursing Home Problems.* There are 95 persons in the area now living in nursing homes who need ENCOR residential services.
- *Community Client Needs.* Although much of the emphasis is on deinstitutionalization, there are many mentally retarded persons already living in the community who someday will need residential care. Services for these persons must be planned and also carried out.
- *Idealogical Standards.* The service system began with a small number of persons who believed unwaveringly in the value, dignity and rights of mentally retarded persons. Their high ideological standards gave them added enthusiasm, energized their efforts and inspired their creativity. As new personnel are employed, extra effort will be needed to keep the ideology rich.
- *Limited, Unstable Funding.* Through the years, the funding from federal, state and county sources has always been in a state of flux—and always short. There have been some increases, but there have also been cuts that have crippled or killed vital components of the service. There have *never* been sufficient funds to accomplish the goal of the Douglas County plan, and there has *never* been a single, stable source of funding from any level of government which is earmarked specifically for community residential services for retarded citizens.
- *Security for Parents.* In the past, when parents placed their child in an institution, the government informally guaranteed that the child would be cared for after they died. No such guarantee has been made for parents placing their child in this community service. This lack of security has led some parents to attack ENCOR when they are forced to choose between it and the institution.
- *Largeness.* As ENCOR becomes larger, there is increasing danger that central management will be forced to develop common denominator policies that enhance one client's life while diminishing another's; or rules that can correct an inefficient staff member's behavior while snuffing out a valuable worker's freedom to create. The organization of the 17 clusters was a defense against such creeping institutionalization. Now, as even they get larger, ENCOR must continue planning to keep each small unit alive, personal and at top efficiency.

The parents, professionals and citizens of eastern Nebraska have invested a massive amount of time, energy and emotion in an effort to provide continuums of residences for the handicapped persons in their midst. In doing so, they have had to deal, one by one, with hundreds of bureaucratic and prejudicial obstacles that have appeared in their way. They have learned that society does not take kindly to those who attempt to correct or change the practices and beliefs it has been institutionalizing for hundreds of years. Nevertheless, these people have not wavered from their goal.

A BOOT CAMP FOR COMMUNITY RESIDENTS

One of the most difficult times in the lives of mentally retarded adults occurs when they leave the safety of a home or institution and move into the community on their own. Such leaps into independence can be disastrous. The many complexities that must be weathered each day can overwhelm the handicapped, break them down, send them fleeing back to the "nest." Parents or caretakers, who already have a tendency to see them as vulnerable, are often all too ready to welcome them back.

Today, many residential service experts have learned that the successful movement of retarded adults into the community involves more than just placing them in suitable quarters. They must be carefully taught to live there, too. While normal persons learn them automatically, there are hundreds of daily living skills that mentally retarded persons must consciously struggle to achieve, one by one, before they can "make it" in the community.

Training for Independent Living,
Oxnard, California

If you are retarded, it isn't your parents or social worker who talk the staff of Training for Independent Living (TIL) into accepting you in their intense, fast moving, residential training program. *You* must convince them. Only your own motivation will get you into the program and keep you there, give you the strength to work 70 to 90 hours a week, accomplish over 150 separate and distinct community living skills and, within six to 12 months, make you ready and eager to try living in the community on your own.

The TIL program has many of the qualities of a military boot camp, where raw recruits are taught and drilled until numerous basic achievements are second nature and the trainee becomes hardened and skilled, ready to cope with what may be a hostile environment. TIL instructors are kinder to their recruits than drill instructors, but no less purposeful in their approach to training. Community living is rough. Knowing this, they are committed to do everything they can to get their trainees ready for it.

The TIL program was developed in 1975 by the Ventura County Association for the Retarded, which was well aware of how frequently retarded persons from homes and institutions fail to adjust to community living. The program utilizes ten apartments that are distributed among 100 units on four city blocks in Oxnard. Since the program is small and personal in its approach, only 24 clients are in training at any one time.

However, the size and approach does not mean that the program is in any way casual. Far from it. TIL is highly detailed in what it demands of the client and in what it demands of itself—so detailed, in fact, that a 365-page manual of training procedures has been developed and is subject to constant revision. This close attention to detail is woven into every aspect of the program:

- *The Intake Evaluation.* A 23-year-old mentally retarded candidate from an institution, Tom Stark, was given an appointment for a full day of intake evaluation at TIL. In the morning, the would-be trainee attended an orientation session. Tom's parents and a social worker who accompanied him were allowed to attend only this first session. After the orientation, Tom was helped to fill out an application for training. Although Tom could write only a few words, the TIL representative was careful never to do for him what he could do for himself.

Following the completion of the application, Tom was given a thorough interview. At this time, a most important question was raised: "Why are you here?" Although Tom did not know it, the interviewer would not have been impressed by such answers as "My mother thought I should come" or "My social worker brought me." Instead, the interviewer listened for the hopes and desires of Tom himself. When he began to tell the interviewer how much he wanted to live alone in the community, the interviewer listened with interest.

The candidate spent many half-hour periods demonstrating what he already knew about bed making, vacuuming a rug, preparing a lunch, operating a can opener, using a stove, washing dishes, calling people on a telephone, telling time, making change and planning a menu. Since he was not expected to do all these tasks, he was helped by the evaluator—but not until he did as much as possible all by himself.

When the day came to a close, Tom was thanked for coming and was told that a letter of acceptance or non-acceptance would be mailed to him within two weeks. Tom Stark left TIL totally exhausted.

- *Acceptance.* As promised, a personal letter was sent to Tom—carbon copies went to his parents and social worker—stating that he was accepted on the conditions that he (1) be enrolled in a day program; (2) make application for a valid California I.D. card; (3) notify the Post Office and the Social Security Office of his change of address; (4) pay a specified amount of money each month for training; (5) be aware that his continuation in the program depended on his motivation and progress; (6) be prepared to enter into a contract with TIL that would be thoroughly explained to him; and (7) notify TIL within ten days if he chose to come for training.

Had Tom received a letter of non-acceptance, it would have been just as exact, giving the precise reasons why he had not been accepted.

- *The Contract.* Tom telephoned TIL immediately, saying that he wanted to come and that he would do all the things outlined in the letter. He then accepted an invitation to meet with a future trainer who would read and discuss a ten-point contract with him.

The contract dealt with the transitional nature of his stay, his attendance at monthly "staffings," his apartment and roommate assignments, training session hours, visitors' rules, the monthly fee to be paid, the need for a day program (in Tom's case, he would be attending a community vocational training program), the equipment he would be issued, and the sharing of cost for food, cleaning supplies and utilities.

When the contract points were clear, Tom and the trainer both signed the contract. The date for his entry into training was set.

- *The Training Progression.* Tom is now in Phase one, the most intensive of three training phases. While in this phase, he must stay with a live-in trainer and two roommates. He attends the vocational workshop during the day; his training at TIL takes place every evening from 5 to 9 on week nights and from 9 a.m. to 3 p.m. on Saturdays. During Phase One, he attends small group training sessions and receives individual tutoring until he can accomplish 148 different community living tasks in ten categories: meal preparation, money management, housekeeping, shopping, appliances, interpersonal relationships, communications, transportation, personal care and safety.

When the required tasks are accomplished, Tom will begin Phase Two. He will move into another apartment with roommates and no live-in trainer. His training activities will include more solo tasks, including assignments in the community.

When Tom enters Phase Three, he will be making " a trial run for independent living." He will remain in the same apartment and carry out tasks on his own initiative, with staff checks being run on him only to see if he is "making it" (e.g., paying his bills, eating properly, keeping his apartment clean, doing his laundry, using community transportation properly). In Phase Three, much of Tom's training will consist of in-the-community seminars on such subjects as comparison shopping and leasing an apartment. At this time, he will be encouraged to purchase many of the items he will need when he finally signs a lease and moves into his own apartment.

- *Recreation and Leisure.* Although the basic training categories are heavily structured, recreation and leisure time is free of performance and evaluations and check lists. Instead, it is seen as a time to break free of all the schedules and rules of the week. Nevertheless, recreation and leisure time is no less active. In addition to the usual activities that agencies sponsor for the handicapped, there are many things that trainees can do in the community, things that range from attending a flea market to going to a symphony concert. Trainees are kept posted on such events by the TIL staff.

- *Moving Away.* If all goes well, the day will come when Tom will sign a lease for his own apartment, take his own furnishings and move away from TIL. However, the association does not end there. The staff will continue to make follow-up visits to his new home and Tom can always return for assistance when his checkbook doesn't balance or when he's attempting to transfer his cooking skills from an electric stove to a gas stove. Tom will also be invited to special picnics and parties attended by both the present trainees and other graduates. And he will probably be asked to give pep talks to the new crop of trainees, just as others did with his group.

Eventually, Tom may lessen even these informal ties. As one TIL trainer describes it:

> It isn't so much that we phase them out. Instead, they phase us out. They begin to say, "Come over and don't make a report on me. Leave your checklists at home. Just be my friend."

And even this may change. It has been documented repeatedly how people like Tom Stark, trained to deal with a new world, find in that world many more exciting things to do than in the old world of the human service systems. When and if that day comes, Tom Stark will sever all contacts with TIL. But that's not bad. As far as TIL is concerned, it could be the best thing that ever happened in his life.

THE INSTITUTION THAT BECAME A COMMUNITY SYSTEM

In the early 1970's, many voices in the community decried the "warehousing" of mentally retarded persons in institutions and called for "deinstitutionalization" instead. But there was something that people in the community did not do. They failed to develop systems of residences that could replace the institution.

Many community groups, of course, did develop a few homes in their neighborhoods. Some of these homes even became "showcases" and the groups pointed with pride at what they had created. Then they stopped. They dabbled with providing residences for, say, 30 mentally retarded citizens, when they should have been organizing for 300.

Meanwhile, the institutions—receiving tremendous pressure from governments, courts, news media and citizens groups—considered giving up their residents. However, there was one big problem: There simply weren't enough community homes to accomodate the residents.

Macomb-Oakland Regional Center (MORC), Mt. Clemens, Michigan

In 1971, the State of Michigan planned to build five new institutions for mentally retarded persons. Two were scheduled for Macomb and Oakland Counties (Population: 1,760,000), just north of Detroit. The Macomb-Oakland Regional Center (MORC) was created to develop the institutions. A superintendent and a skeleton staff were hired to develop the first 650-bed campus; however, the new superintendent and his staff made a bold request. They asked for permission to put the building plans on "hold" until they saw what residences could be developed in the community. After an initial survey, it became clear that sufficient community residences were not available and wouldn't be for a long time. So MORC began developing a community residence system all by itself.

Today, the institution is organized into a series of community residences, each effort energized by the same unifying goal: to prove that Macomb and Oakland Counties do not need self-contained, central institutions.

In an effort to accommodate everyone in the community who wanted to take an active part in keeping the handicapped out of the institution, MORC came up with two kinds of community residences, each with its own offshoot:

- *Community Training Homes (CTH).* Although these homes are sometimes viewed as "foster homes," they are really more than that. They not only provide the usual room, board and supervision, but offer intensive developmental training as well. At present, there are 250 developmentally disabled persons who live in these homes with 150 families throughout the region.

Occasionally, a CTH family will express a desire to do more. Rather than just assist mentally retarded persons on a part-time basis, the family is willing to work full-time and provide even more intensive services. To accommodate such families, MORC has established *Alternative Family Residences (AFR).* These residences provide intensive in-home training for not more than four persons with more extreme handicapping conditions. There are, at present, four AFR's in operation.

- *Group Homes.* Some community residents who want to help mentally retarded persons would rather do so on a corporate basis rather than on an in-the-family basis. For such residences, MORC has established a series of group homes, each of which operates under its own corporate structure, governing board of neighborhood professionals and nonprofessionals, and three shifts of residence managers who do not live in the homes. There are now 30 group homes serving 250 developmentally disabled persons in the area. Although the homes have a maximum limit of six residents, three of the early untis (organized when the program was still in its infancy) still contain from 14 to 18 residents. However, since MORC believes that these larger units tend to take on the characteristics of institutions, efforts are being made to split them into smaller groupings.

Here, too, there is a creative offshoot. Recently, five group homes met the Federal Government's Intermediate Care Facilities standards and, as a result, now receive HEW funding. These homes—known as *Alternative Intermediate Services (AIS)*—also accommodate no more than six residents, but they do provide services for persons with more intense handicapping conditions.

A handicapped person is never immediately accepted for a MORC residence as long as that person has a home in the community. Before

Community Residences

acceptance is considered, parents or relatives are trained within the home to help the client. MORC is prepared to move staff members into the home to help the family solve the problems calling for the client's removal; if the situation calls for 24-hour service, then MORC will supply that, too. As a result of such services, half of the families serviced develop to the point where they are willing to keep the handicapped relative in his or her home. If the situation remains unchanged, of course, other residential arrangements are made for the handicapped person.

Despite the efforts of MORC staff members to phase out institutionalization, the state nevertheless mandated four years ago that a 90-bed institutional unit be constructed. The mandate, however, turned out to be more of a victory than a defeat for MORC. The "institution" consists of many small, duplex-like housing units, with each unit housing eight residents (four on each side of the duplex). The units are small and homelike, which, MORC believes, is all to the good; but they are all situated on the same site and that smacks of "institution." Nevertheless, MORC is managing to live with the situation, since the facility is used only as a depot for bringing the last 600 Macomb and Oakland County citizens out of institutions across the state and eventually placing them in community residences. In the 18 months that the 90-bed unit has been operating, only two persons have been admitted from the community.

Although MORC's case load is constantly changing, with some persons being admitted to the program and others being phased out, there are approximately 700 clients being served at all times. Eighty percent are persons with severely and profoundly handicapping conditions.

To deal with such a case load, MORC has organized a number of divisions which perform specific functions in the setting up of each new community residence. Each division carries out a highly detailed checklist of functions, each of which must be carried out satisfactorily before a client is admitted. To make matters even more complicated, new tasks are being added continuously. Such meticulous planning, MORC believes, is necessary if the community wishes to develop a no-nonsense residential system that will serve all handicapped persons, not just the chosen few.

- *The Recruitment Division* has one single goal: to give the program the maximum publicity it deserves. "We are the ones who make the telephone ring," said the division director. They are on the phone constantly, planning and carrying out a thorough campaign of advertisements and presentations in newspapers and on TV and radio. They also set up speaking engagements in all towns of the two-county region.
- *The Home Finders Division* follows up on all likely prospects for community residences. Some members of the division interview families, screen them in or out, check letters of reference, help them qualify for licensing and arrange for trial visits of handicapped persons in the home. Other members are experts in developing neighborhood, non-profit corporations. This includes finding investors, organizing local governing boards and recruiting lawyers to draw up corporation papers. When all the details are settled, MORC "vendorizes" the group home and provides for the placement of residents.
- *The Case Manager Division* takes over after the Home Finders have set up the home. The members of this division receive written reports (on the status of homes, problems, etc.) and conduct monthly meetings in the home. They coordinate the development of the individual program plan, as well as its quarterly and annual review. They are also available to deal with any critical situation that may arise.
- *The Program Review Committee* handles the admission of clients. This committee is composed of professionals from generic agencies, MORC staff members and parents of handicapped children in the community. It meets twice a month and considers an average of 15 referrals at each meeting. Of the 30 referrals received each month, only four are finally accepted for MORC residential services. The others are carefully assisted into other more appropriate generic service programs or into in-home training.
- *The Professional Consultant Staff* consists of physicians, dentists, nurses and physical, occupational and speech therapists. The staff treats clients only as a last resort; instead, it enlists the services of other professionals and agencies in the communities. If no such agencies exist, the staff works to develop them.

MORC's training programs never stop. All home managers receive a thorough initial training that consists of an orientation on mental retarda-

tion; maintaining healthy environments; providing emergency care; fire and safety condsiderations; administrative responsibilities; the elements of programming; and the principles of normalization. Each training unit requires approximately three hours to complete, and continuing education takes place at the rate of two hours a month.

MORC believes that its community residential system has probably not been duplicated elsewhere. One staff member explained: "We built this system for two heavily populated counties just north of Detroit. It's for the specific needs of these citizens only." However, this hustling organization has developed a series of principles that other communities may wish to consider:

"There is no such thing as a permanent placement." All of society out grows certain facilities. It is expected that mentally retarded persons will do the same.

"There will never be a complete service system." Something will always be lacking. There will never be enough varieties in residences.

"Our workers are expected to work hard and burn out." MORC accepts the fact that it has a 25 percent employee turnover rate and that the average stay is only three years. It is what happens to the workers while they are on the job that is important: few staff members come to MORC with up-to-date attitudes toward retarded persons, but most leave with a healthy philosophy. Many leave to take much better positions in the field of mental retardation; indeed, there are strategic positions throughout the nation which are held by alumni of MORC. One staff member put it this way: "MORC is seen as a good place to move from."

"Developing parent trust is a must." Communication with parents through newsletters and personal conversations is being constantly improved. Parents must approve the home where their child is placed. Once the child is in the home, parents are able to contact MORC 24 hours a day.

"When a community home placement breaks down, we must have alternatives ready other than the institution." MORC plans for a number of alternative options. In fact, the organization seems willing to do almost anything to keep a retarded person out of the institution.

In spite of all the ingenious organizational creations and the fresh principles that motivate them, MORC staff members admit that they still have an uphill battle to fight. More and more people with retarded children are moving into Macomb and Oakland Counties from the Detroit area. One reason for this influx is certainly due to the fact that MORC's achievements have received considerable publicity, with the result that many families have moved to the area for the express purpose of securing services. In addition, 150 developmentally disabled persons still live in nursing homes, and these people—according to MORC standards—must be relocated.

Nevertheless, MORC is an agency that is struggling valiantly to deal with the residential needs of *all* retarded persons in the region. MORC definitely knows where these people are and what needs to be done, and is committed to the development of a system that is comprehensive. Although MORC is well on its way to reaching its objectives, it remains to be seen just how far the organization will actually go. This, however, may be significant: MORC is already thinking about how the 90-bed unit with its central heating system and swimming pool can be used for something that is definitely non-institutional.

A RURAL COUNTY TAKES CARE OF ITS OWN

Many Americans cherish living in a rural setting and wouldn't have it any other way. Mentally retarded citizens, however, often have no choice as to where they will live. They are forced to move to the cities simply because the rural areas cannot provide the special programs they need.

Until recently, this forced move to the cities was the fate of most mentally retarded Americans in search of special programs and services. Today, a growing number of rural communities are reconsidering the many complex questions that pertain to helping the handicapped. They are learning that although most technical skills and standards are developed in urban settings, there is no reason why rural communities can't have their own programs, too.

Tuolumne County Independent Living Project (TCILP), Jamestown, California

"We who live in these mountains are different. We like the way we are and we don't intend to change. But something aches inside when our handicapped children must move to the valley for special programs. They get help, but something is lost in the process." So spoke the mother of a teenage son with cerebral palsy and mental retardation. To enroll her son in programs for persons mentally retarded outside of her mountain community was somehow a surrender. She, like many others in Tuolumne County, felt deeply that it was the community's moral duty to take care of its own. The end result of this community ethic: a local residential program that is remarkable because of its simplicity, naturalness and low cost.

Four apartments for developmentally disabled persons are interspersed in a recently constructed 44-unit complex in this mountain town of 950 persons. Nine handicapped individuals—from 19 to 32 years of age—make their homes in these apartments. Three of the men live semi-independently in a three-bedroom apartment; three women have a similar arrangement; two men with more severe handicaps live in the same apartment with the project's salaried house manager; and one person lives independently in a smaller apartment.

During the day, all of the handicapped residents attend a work activities center two miles south of Jamestown. In the evenings and weekends, they are members of the community. They interact with other residents on the street, go bowling, attend movies and eat in local restaurants. They are invited for dinner in other homes in the neighborhood; and, in the case of two women who have learned to cook reasonably well, entertain townspeople in their apartments. The handicapped men also accompany neighbors on fishing trips to the many nearby mountain streams. Although most of the interactions are spontaneous and informal, both the clients and the project's volunteers have sponsored special pot-luck dinners for selected persons in the community who might be interested in regular friend-to-friend relationships.

The handicapped tenants are so well accepted as neighbors that the manager of the apartment complex has indicated that he would like to rent more units to such persons. The offer has been declined with thanks, however, because too many units for handicapped persons in the same complex might possibly adversely affect the excellent relationships that are now being established.

Tuolumne County's belief that it could take care of its own is neither an idle boast nor a case of wishful thinking. The residential program is remarkably self-sufficient:

- TCLIP is financed, for the most part, by the handicapped resident's Supplementary Security Income (SSI) checks. Each client pays a share of the rent, the utilities and groceries and the salary of the house manager. After all these costs have been deducted, each client has money left over for personal use.
- No licenses are needed for the operation of the program since the clients pay their own rent and sign their own apartment leases.
- The project is administered by a non-profit corporation of volunteers. The corporation's board consists of *all* of the handicapped residents, one of the County Supervisors, the County Assessor, a parent of a mentally retarded child, the director of the work activities center and a representative of the Valley Mountain Regional Center (VMRC) which covers three mountain and two valley counties—one of 21 state mandated regions—with headquarters in Stockton. A volunteer serves as the project's bookkeeper; other volunteers have donated furniture which was refinished at the work activity center by the clients themselves.
- The project has received support from the Catholic Charities Semi-Independent Living Project (a "Vendorized" program of VMRC) to pay for the relief staff on the house manager's days off. VMRC also pays for the clients' transportation to and from the work activity center and provides a community worker who coordinates individual program planning and remains on call for emergency assistance. This support, however, is minimal compared to the responsibility undertaken by the clients themselves.

Since the program began in 1976, the residents of Tuolumne County have discovered that six citizens live in institutions. Although these citizens have been institutionalized for some time and are severely and profoundly handicapped, TCILP has started to plan for the development of a group home for them in the community. Not only is TCILP determined to bring all institutionalized persons home, it also intends to prevent such institutionalization from happening again.

While the county continues to complete its own residential programs for handicapped persons, the larger VMRC is well on its way toward developing a computer-based program of individualized residential services for every developmentally disabled person in the five-county area (which has a population of slightly over 600,000). VMRC is "vendorizing" many non-profit organizations like Catholic Charities, which, in the past year alone, has opened 45 new apartment units for handicapped persons. It's also working closely with Stockton State Hospital, transferring the mentally retarded residents there to community settings.

The state mandated monitoring agency for the region—Area VI Developmental Disabilities Board—has announced that a continuum of community residences is its top priority. In addition, the special education and psychology departments of the College of the Pacific in Stockton have contributed generously of their expertise to the community residential effort.

Such large-scale, region-wide efforts are highly beneficial, of course, but they can pose a threat to small, indigenous community projects like TCILP. What are the chances of TCILP one day being swallowed up by the five-county organization? The director of VMRC has this to say: "Such beautifully self-reliant programs must be protected and supported by the Valley Mountain Regional Center. If everybody did what Tuolumne County is doing, and if everybody kept improving the services, the day would come when VMRC would no longer be needed.

"In the meantime, we must continue to organize residential services for the many other citizens who need it, but we must do it so the larger five-county programs and the smaller, community-initiated programs coexist. Furthermore, we know only too well that the urban valley culture and the mountain culture are remarkably different and we are committed to protecting and reinforcing the integrity of both groups."

Photos by Tuolumne County Independent Living Project

Work

The Donut Shop
8808

THE PUBLIC SERVICE CREWS OF GREATER LOS ANGELES

Competitive employment has been a major goal in preparing mentally retarded persons for adulthood. With many new training technologies now available, more handicapped citizens will be gainfully employed than ever before.

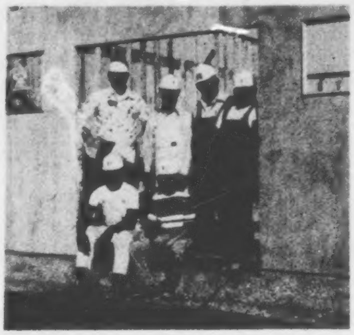
But what about retarded individuals who can't compete? Must all of their working lives be spent at a table in a sheltered workshop, performing such undemanding tasks as putting picnic spoons in plastic bags? A workshop trainer on the West Coast hopes not:

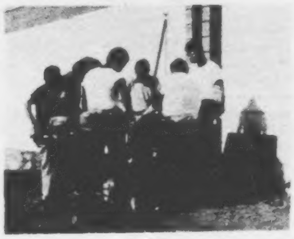
> I've worked with most of these adults for three years now, and I can tell you some of them are bored. They've learned to sit for long periods, look appropriate, increase their production and not complain. But I can sense that people like Bill and Maggie (nodding toward two persons packaging faucet washers) find no challenge in their work anymore. I suppose neither will be able to take the giant step into the competitive market, but I feel they could do more than they are doing now.

Community Redevelopment, Center in Mental Retardation, California State University, Los Angeles, California.

Eric Rodriguez loves going to work. On the day he was interviewed, he was up at 6 a.m. and on a city bus by 6:20. During the next 90 minutes, he transferred twice, walked five blocks and arrived at his current job ten minutes early. While saying good morning to the other members of the six-man crew, Eric walked into a portable shed, put on his hard hat, strapped on his tool belt, opened his personal tool box and filled his holsters with the tools he needed for the day's group effort, constructing a playground for children. The only things that could keep Eric from such steady public works labor would be something like a bus strike or severe illness. Even the fact that he can read neither numbers nor street signs and does not receive a competitive wage has not kept him from this job.

On this particular day, he and the other members of the crew—all of them handicapped—constructed





wooden forms, shoveled sand and worked with wet cement. But that's only a small part of the crew's repertoire. In the past 16 months, this work crew—and four more like it—have constructed sheds, built wheelchair ramps, painted interiors and exteriors of buildings (mostly public schools and private rehabilitation facilities) and remodeled restrooms for handicapped persons.

Eric is now 22. Unlike many young, mentally retarded adults, he feels very much like a creative adult and going to work is sheer fun to him.

The work crews came into being in June, 1975, when a small grant entitled "Community Redevelopment: An Alternative to Workshops" was awarded to California State University by the Region IX Developmental Disabilities Office. The project called for the development of small close knit work crews, each containing five mentally retarded adults who previously had been evaluated as "not feasible for competitive employment." The sixth member of each crew was a non-handicapped "lead worker" who possessed previous experience as either a construction worker or a college industrial arts student.

The project has been so successful in its community service efforts that it has been continued on its own after the grant expired in the Summer of 1977. Costs are remarkably low: the lead worker is salaried by the Comprehensive Employment Training Act (CETA), while the handicapped crew members live off their Supplemental Security Incomes (SSI) of $296 per month, as well as a monthly $60 payment from the local California Regional Center. (If they received any more payments, they would no longer qualify for SSI.) The organization being served is expected to pay for the materials and the expendable tools only.

Some striking principles have emerged from the operation of this pioneering public works program:

- *Competitive employment principles are diminished.* Money is not a primary motivator. Nor is production tempo. "We don't care if a project takes one week or three weeks," said one lead worker. "What counts is that the workers' interest and enthusiasm remain high and that they observe all standard safety procedures.
- *Personal value comes from helping others in dignified ways.* There's nothing "devalued" about these workers. They are helping to make the world a better place in which to live and they know it. Their heightened sense of value is even carried into their homes. One lead worker explained:

> Some of the fellows take home blueprints and spread them out on the kitchen table to show their dads what they're doing. They may not be able to read the words, but they can point to the various components and describe them. For some of the workers, this has been the first time their fathers ever took an interest in anything they did.

The project director pointed out that "we've learned never to underestimate the personal values that come from wearing a tool belt, a hard hat and having one's own tool box. These items tell others that a guy stands ready to perform no-nonsense labor that can even be dangerous."

- There can be power in creative comradeships. Community Redevelopment has borrowed and modified "the peer group principle" developed by Emanuel Chigier of Israel. One leader explained the principle as he saw it:

> None of these projects could ever be completed by any of the workers alone, but together they become a remarkably powerful construction force. That is why we emphasize the fact that they belong to a damned good group. We train together, we work together and we even recreate as a group.

- Independent living skills are relevancy-based. There are no predetermined courses of study for the workers. Instead, the projects themselves dictate what the workers must learn. For example, travel training must take place each time a crew moves to a new job location. Each worker must learn new bus routes and identifiable landmarks between his home and his job. Learning to write or print their names, addresses and telephone numbers becomes critical.

Another immediate necessity is the budgeting, saving and spending of money, and the handicapped workers become highly teachable regarding money management. Even when they go together to restaurants, on picnics or on weekend camping trips, every detail of such ventures provides an agenda for learning to live a richer, more independent life. One more example: The crew was refurbishing a large house for a rehabilitation facility and it was decided that the kitchen would be completed first. Then, each man took his turn planning, shopping and preparing the noon meal for the entire crew. The supervision of this training diminished as each worker became a capable cook.

- Alliances between mental retardation professionals and industrial professionals are highly valuable. Formal dialogues and affiliations with agencies and departments having different perspectives have enhanced the creativity of the project. For example, a close working relationship has taken place between California State University's Center in Mental Retardation and the Industrial Studies Department. As a result, the industrial arts personnel have become avid contributors of technical advice on construction projects; they spend long hours drawing blueprints that are easy to understand and carry out, and they help lead workers develop instructional methods. Some industrial arts students have become so interested that they have joined the project as lead workers themselves.

From innovative principles like these, one begins to see that if a mentally retarded person cannot successfully compete for a job, all is not lost. Many opportunities still exist for them to join with comrades in renewing and redeveloping parts of their community. And as the community gains, so do each of the handicapped workers who receive tremendous dignity and status from their work.

One of the project directors feels this so strongly that he has developed an attractive national perspective on such community service efforts:

> Right now, the Federal Government is trying to develop a welfare reform program that will separate those who can work from those who cannot. And would you believe that our handicapped workers are seen by the government as being among those who cannot work? What a shame! These men *are* working now. They *know* they have something rich to contribute to society. They feel it so strongly that they often come to work sick and we have to send them home. It would be sad if these men are ever seen as non-productive citizens and are sent home to live off the dole and watch TV all day . . . Just last week, I was in a subway station on the East Coast and it was in horrible disrepair. It made me want to bring our work crews to the city to begin working on these stations one by one . . . Wherever I go, I see hundreds of public works projects that need to be carried out and I know of many retarded persons who could be tremendous forces in community redevelopment if we organized them right and valued them for the no-nonsense contributions they could make to the nation.

JOB TRAINING THAT INDUSTRY UNDERSTANDS

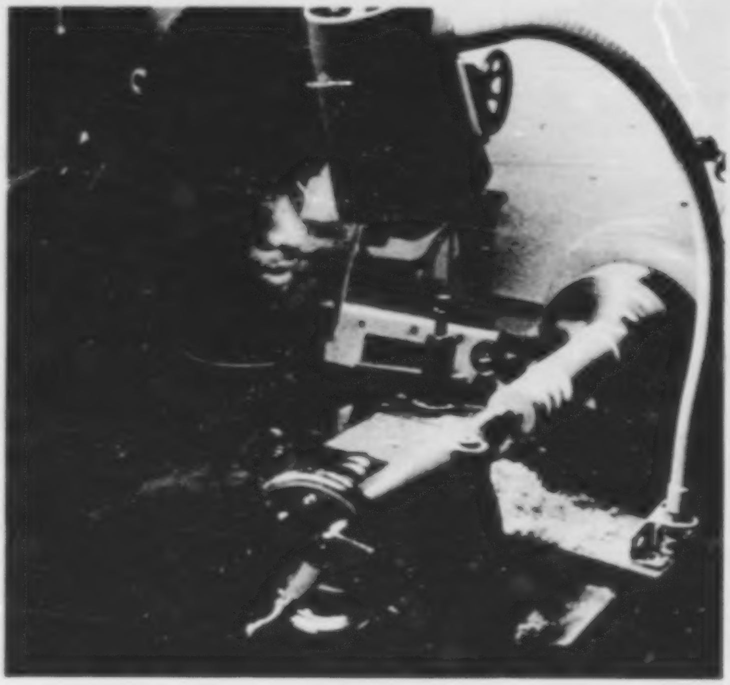
Until just recently, mentally retarded citizens had no place in the nation's labor force. There were exceptions, of course, where "charitable" employers carried handicapped employees on the payroll—but they did it more from feelings of sympathy and guilt than from the dictates of sound business practices. Today, however, many mentally retarded persons are working side by side with non-handicapped employees. Management is learning that, far from being merely a sympathetic gesture, the employment of mentally retarded persons can be a sound business strategy.

No one knows how many retarded persons will eventually fill competitive job placements in industry, but if the diverse types of new-breed vocational trainers have anything to say about it, thousands of handicapped persons will be accepted as members of our country's labor force.

Training Alternatives for Living and Learning (TALL), Kansas City, Missouri

When a placement worker from this small, hustling, avant-garde, vocational training unit approaches an employer to discuss the hiring of a TALL client for a specific job opening, there's no defensiveness in his approach. There's no gingerly holding of hat in hand, nor saintly expression, nor enticing the employer to feel sorry for the client. Instead, a hard-nosed business deal is offered.

The placement worker goes over the employer's detailed list of skill requirements and may even add a few more requirements from the Dictionary of Occupational Titles (DOT: the nationally accepted industrial reference for detailed skills, produced by the U.S. Department of Labor). Then, component by component, the TALL representative goes over the handicapped person's profile with the employer, showing that this potential worker can meet every employer and DOT requirement. TALL stands ready



to help, if need be. For example, even if the client has severe physical limitations—and most clients do—an industrial engineer from TALL will attach prosthetic modifications, at TALL's expense—to the equipment the handicapped person will use.

After such discussions have concluded, the employer is often amazed because the placement worker—who was expected to be a "social service type"—turned out to be a no-nonsense businessman who talked the employer's industrial language. And, by skillfully matching the employer's data with the client's profile, the placement worker is frequently able to convince the employer that what his company stands to gain is a good, productive worker.

A TALL trainee learns to operate a typewriter using a breath device

TALL's placement procedures are admittedly extraordinary. And so is the systematic process used in getting a handicapped client ready for employment. The process contains the following components:

- Ample time is allowed during the application period for the agency and the trainee candidate to size each other up. The candidate's records from other agencies are released and read. Discussions take place, with the candidate having the opportunity to ask as many questions as he or she wishes. The goal, in TALL's scheme of things, is not to screen for the cream of the crop, since all clients have severe handicapped conditions (75 percent are mentally retarded) and all have failed in other vocational training programs. Instead, TALL workers look for a person with dormant possibilities and with enough motivation to try one more time to get a job in industry.
- On Commitment Day, the candidate meets with TALL's training director and two prospective trainers in an intensive closed-door session. In this meeting, it's made clear just what stringent training components the candidate is expected to undergo. It's also made clear that the trainers are vigorously committed to discovering and reinforcing every strength—not weakness—in the handicapped person which could lead to a full time job in regular industry. Finally, the candidate signs a statement of intent that he will adhere to all rules and policies, including a full Monday-through-Thursday work week, with the only acceptable excuses for absence or tardiness being illness or death in the family.
- Immediately after Commitment Day, an intense, three-phase assessment process begins—not to exceed two weeks, nor be less than 20 hours—that covers 170 ordinary living skills, 144 work behaviors and not less than 74 work-related physical skills. When the assessment is completed, TALL professionals have a lengthy, highly detailed list of the client's skills.
- Once all the assessment information is in hand, a strategy meeting takes place, at which the client, training director and two assigned directors go over all the client's strengths. Then, together, the handicapped person and the TALL trainers plan specific training milestones that must be achieved in the personal, industrial and physical areas. This is the first of many strategy sessions. Regular sessions are held at least once a month, and client or trainer can call for an emergency meeting at any time.
- At this point, the client becomes involved in an on-the-wall, visual charting process. His name is entered on a large gridded chart with the names of other trainees. This easy-to-read chart—which covers an office wall, from ceiling to floor—records each client's progress through seven basic training phases and 20 sub-phases. The client's movement is charted through assessment, basic self-care, pre-vocational skills, career exploration, skill training for a specific job (DOT number and description are listed) and hiring by a company. The chart makes it possible for the client and trainers to see where each handicapped person is in his or her training program at any given time. It also dramatizes the fact that within four month's time, a handicapped person is expected to have moved toward a specific job in a specific industry.
- If necessary, the industrial machinery can be modified, enabling a client with severe handicaps to meet regular production standards. TALL has available a full-time industrial engineer who is prepared to develop special machine controls activated by tongue, breath, eye contact, light, sound, body heat or proximity, touch and slight body movements. Such prosthetic modifications can be easily attached and removed from all kinds of machines on an assembly line. However, such adaptions are constructed only after the handicapped person's own skills are at a maximum.

Although the TALL program has been in operation for less than a year, it has already served 46 handicapped clients. Twelve are working full time on assembly lines, in food service systems and in clerical positions. Twenty are now being groomed for specific industrial positions and the remainder are in the early phases of training. There have been six failures: one client simply could not keep up mentally and physically; two moved to other areas of the country; and three came to the realization that if they were employed, they would lose their monthly SSI checks and thus chose not to continue training.

This new, lively vocational effort trains only severely handicapped persons who heretofore were never able to qualify for full time jobs in regular industry. Far from dismissing the program, tough-minded businessmen from the greater Kansas City area are highly interested in what is being accomplished. For example, Kansas City officials of Montgomery Ward made on-site visits to the TALL training location. They observed the operation in action and looked closely at the systematically recorded data on clients. They were so impressed by what they saw that they gave TALL the complete encyclopedia of detailed job descriptions for all positions in the Montgomery Ward industry, stating that they were willing to consider handicapped clients who could meet specific job descriptions.

This vocational training program is based so strongly in the principles and language of regular industry that one industrial expert predicted the day would come when larger industries will develop such vocational training systems within their own corporations. If they do, they stand to gain enthusiastic, stable, regular attending, skilled employees who heretofore have been passed over by the nation's industry.

IN THE REAL MARKET PLACE

There was a time, not so very long ago, when many industrial training programs for mentally retarded adults were conducted in simulated work settings that were located apart from the real world of work. The programs were usually well-meaning and sometimes beneficial. However, they had one big drawback: The step from artificial training program to real industry was so great that even so-called normal persons would have had a hard time making it. Today, industrial trainers have begun to help retarded persons bridge this frustrating gap between training and employment by bringing the vocational training program as close as possible to the practices and locations of regular industry.

Photos in The Donut Shop by Dan Tichonchuk

THE
DONUT
SHOP

The Donut Shop, La Mesa, California

"Everything is real here—the cash register, the display cases, the tables and chairs, the baking equipment in the back. But most important of all, the customers and the employees are real, too." So spoke Al Filipponi, creator and manager of a popular little bakery, located in the center of downtown La Mesa. His penchant for realness, however, stems not only from the fact that the Donut Shop is an attractive thriving business; it also comes from his determination to make the shop an industrial training center where mentally retarded trainees are integrated with regular employees in a genuine marketplace effort.

It all began two and a-half years ago when Filipponi, the father of an 18-year-old, mentally retarded daughter, left his position as a successful manager of a life insurance business and began to create his own conception of a successful work training program for mentally retarded adults. It was a make-or-break effort for him, since he had invested all of his funds in the project and was working on it full time.

Today, the Donut Shop is a unique success in more ways than one. The shop produces and sells many different kinds of donuts and pastries . . . there is a pleasant area containing tables and chairs where customers can eat baked goods and drink coffee . . . and the store is open from 5:30 a.m. until 6 p.m., while the bakery operations begin at 2 p.m. and end at 11 p.m.

The business employs three bakers, five salespersons, an administrator and a vocational teacher. An average of 12 mentally retarded vocational trainees work side by side with the regular employees in this unique, learn-by-doing enterprise. A small house behind the Donut Shop has been converted into a classroom where the trainees participate in job-related learning activities.

Today, all trainees are "verified" as being developmentally disabled adults by the California Department of Rehabilitation and they receive financial support. However, the verification took place only after the Department heard about the program, investigated it and became so impressed by the program that they offered to "vendorize" it.

Filipponi's program involves many sensible, easy-to-understand principles and practices. They are best described in his own words:

- *Initial Interviews.* "I find there's not all that much difference between interviewing a prospective insurance agent and a mentally retarded candidate for vocational training. The rules are the same and we look for the same basic things. It's still a case of an employer interviewing a job applicant from a strictly business point of view

"Of course, the most important thing we keep looking for throughout the interview is motivation. Nobody can produce very much without it. We even make it clear to the parents and the counselors who bring the

Photos by Dan Tichonchuk

retarded persons for the interview that it's the applicant's *wanting* to learn the bakery business that counts.

"During the interview, we see that they level with us about their handicaps. We want them to tell us what medications they are taking, what kinds of seizures they may be having and why they aren't using that crippled hand they seem to be hiding."

- *The First Two Weeks.* "If they are accepted for training, we have them agree to stay with us for two weeks, no matter what happens. At the end of that period, they can tell us what they don't like about us or the bakery and they can quit. On the other hand, we intend to tell them how we see them after two weeks as well. Quite often, mentally retarded persons become frightened in a new setting such as this and they want to escape—so we do everything to hold them steady until they are no longer afraid.

"In these first two weeks, they are exposed to jobs in the front—cleaning tables, arranging pastries in the display cases and giving samples to customers. Then, they do various jobs in the bakery, from washing pots and pans to working with the dough. They also spend time in the classroom working on job-related learning tasks that involve using the cash register, making change, learning proper sales communication with customers, using the telephone and making out time cards. These people haven't worked before and they need to get many things straight in their minds about working. By the end of the first two weeks, we are ready to assign them to the group of salespersons in the front or to the bakery crew in the back."

- *Sales Training.* "Everybody begins by being afraid of the cash register, but that's the easy part of selling and we help them handle that problem quickly. The toughest task is training them to do a good job of selling. They must learn not merely to say to a customer, 'Can I help you?' Instead, they must develop confidence in saying things like, 'Good morning, how are you today? We have some wonderful cinnamon rolls this morning.' It's gracious statements like these that get an extra fifteen dollars in the till. That's the kind of salesperson every boss wants. And because these trainees are handicapped, we intend to make them better salespersons than so-called normal people.

"There are many little things that good salespersons must learn. For example, the effective display of pastries and skillfully knowing where each should be placed for the best sales are both important. The ability to be properly groomed allows them to meet health department standards and to be attractive to the customers as well. These are the little things that sell donuts—and selling is what this job is all about."

- *Customers as Teachers.* "Most customers don't know that they are the best trainers we have. From them, our trainees learn to understand all kinds of people, even the grumpy ones. For example, we had a retarded young lady who was extremely shy, so we gave her a tray of bakery samples and told her to go out and give them to the customers. She received so many kind responses from people that her shyness disappeared almost immediately. Giving samples to customers, pouring them an extra cup of coffee and listening to their responses are excellent training devices."

- *Bakery Training.* "Those we train in the bakery work side by side with the bakers until they know everything about preparing and baking different kinds of dough. They learn to weigh the portions of dough and water, as well as to measure such things as yeast, nuts and flavors. Since we are mechanized, the trainees learn to work with mixers, the proof box where the dough is raised, the glazer, the donut dropper and the friers, each of which contains 200 pounds of very hot shortening. They also become skilled in making various handmade pastries."

- *Corporation Titles.* "When the plan to become a nonprofit corporation was read to some of those working with us, one responded by saying 'Hallelujah.' He said it in such a joyful way, we decided to name ourselves 'The Hallelujah Corporation.' After all, it sounded so much better than the usual pity-getting names that some corporations use. We want to be happy and strong!"

Since the opening of the Donut Shop, 28 persons have moved through the training program to other jobs. Many are working in fast food chains, ice cream shops and family restaurants. Those who have developed into pleasant, over-the-counter salespersons have found a wide choice of jobs waiting for them. Also, each trainee leaves the Donut Shop with completed applications for his next job and with a remarkably elaborate resume. After all, when they leave this unique training center, they do have a job history of which they can be proud.

Hallelujah Corporation is now expanding to other "mainstreaming" vocational training efforts. For example, the corporation now conducts a housekeeping program in a 54-unit motel in La Mesa. Ten mentally retarded persons are involved in this program.

The members of this corporation are adamant in their belief that mentally retarded persons best learn how to live and work in the real world by actually living in it. They have no use for isolated, artificial training efforts. Instead, they expose trainees to the genuine components of a community and industry—especially customers.

One last point about customers as trainers: Any visitor sitting at a table in the Donut Shop, eating a donut, drinking coffee and listening to the many conversations which take place over the counter, can easily see that those purchasing the pastries are receiving a rich education, too.

Self Assertion

WE ARE PEOPLE FIRST

A gentle protest can now be heard throughout the nation from mentally retarded persons who are tired of being over-protected. They have begun to object when professionals and non-professionals make decisions for them and speak for them, when, with a little time and patience, they could have decided and spoken for themselves. These first protests are, perhaps, the latest step in a natural evolution: They have come out of groups of handicapped persons in community settings where new styles of organization have enabled individuals to speak more genuinely about themselves than ever before.

The protests are still gentle. However, as the community organizations gather strength and momentum, they may become more demanding. Mentally retarded persons may start reacting like the rest of us; when others attempt to do things for us that we are determined to do for ourselves, we have ways of telling them to back off.

Photo by People First

People First, Salem, Oregon

National attention has begun to focus on "People First Conventions," a young and thriving movement of developmentally disabled persons who organize and carry out their own convocations with little help from non-handicapped persons. The first convention was a state assembly which was held at Otter Crest, Oregon, on October 12-13, 1974. The convention, which was attended by 560 persons, had as its theme, "We Have Something to Offer." A second convention was held the following autumn at Bend, Oregon, with 750 in attendance and, from that time on, the movement has expanded rapidly. Similar conventions have convened in California, Kansas, Washington and Nebraska, as well as in the provinces of Ontario and Alberta. Regional meetings have embraced six states at a time and some conventions have drawn over a thousand participants.

As a result of the movement's obvious success, some states have become interested in applying for grants in order to "buy" such conventions for their own developmentally disabled residents. Such searches for funds reveal that some state leaders may have missed the whole point of the People First movement. Far more serious: The assemblies that such uninformed leaders create may, at best, be artificial and superficial.

The first convention was two years in the making and was the unforseen product of follow-up relationships between former residents of the Fairview Hospital and Training Center (FH&TC) and some of the institution's social workers. Throughout the Salem area alone, these social workers conducted 23 weekly support group meetings. One FH&TC staff member explained why they were needed:

> Our former residents seemed to be moving into the community like immigrants coming into a new country. They couldn't seem to be their own advocates. Others conned them into doing things they shouldn't have done and they had a hard time expressing what it was they needed in order to survive in the community. They needed to 'unwind' what they learned in the institution and we were committed to keeping them from returning to the institution.

The support group processes took some surprising turns. For example, it was learned that one handicapped person sometimes had a special knack of understanding what a comrade was going through. And sometimes he had a down-to-earth way of telling the struggling comrade what to do about his problem. The social workers, observing such friend-to-friend solutions, had the good sense to discuss this phenomenon among themselves and to develop detailed procedures for reinforcing it. The procedure clicked and an outstanding "peer-group support system" was born. Then, it dawned on everyone that as the handicapped persons were talking more and more, the social workers were talking less and less. It was the first indication that handicapped persons could indeed take charge.

A similar evolution was taking place in Canada. Two FH&TC staff members and three handicapped persons attended what was billed as "the first convention for the mentally handicapped in North America," in British Columbia. Hearing so many mentally handicapped persons speak out about their own situations was a heady experience for the five visitors from Salem. When they returned, they shared what they had seen and heard with other support group members. The group members were ripe for such talk as this and they discussed what happened for many weeks. Finally, it was decided that they would launch their own convention.

Seven months were spent learning everything they could learn about such conventions—what they are, how they are conducted and what detailed tasks must be carried out in preparation. Elected representatives from all 23 support groups came together to form a core planning group. Officers were elected. Then, in the fifth month, they decided their organization should have a name, and one was voted from 12 possibilities when a member said to the group: "We are tired of being seen first as handicapped, or retarded, or developmentally disabled. We want to be seen as *people first.*"

The convention had barely started when there were two strikes against it. First, 200 participants were expected and 560 showed up. Second, the leadership—sincere, but very unsophisticated—got mixed up so that the last item on the two-day business agenda was presented first. Nevertheless, the "helpers," understanding these conventioneers and believing in them, stepped back and allowed them to solve things in their own way.

Old institutional friends found each other; they hugged, laughed and talked together. Impromptu and planned speeches were given, and individuals talked about themselves, where they lived and worked and what they wanted to do in the future. Meals were eaten, a dance lasted until 2:30 a.m., church services were attended and walks with friends on Oregon's picturesque seashore were taken.

An uninformed observer might have thought the convention a shambles, but in the minds of the participants it was not. Almost everything that had happened to them was sheer beauty, an experience that many will remember for as long as they live.

In the closing moments, there was a rousing, unanimous vote to have another convention next year. And, as many handicapped persons said their goodbyes and their see-you-next-year's, it was evident that these people had caught a contagious convention fever that continues to spread even today.

The experience at Otter Crest and during its two-year preparation period has cast new light into some of the shadowed corners within the field of mental retardation. Some of these innovations are:

- An organized mechanism that encourages handicapped people to speak for themselves in large assemblies (and in small ones, too) was born. One helper explained the breakthrough as he saw it:

> Many of these people have been participants in conventions held by professionals and voluntary organizations, and when they tried to speak out in their unsophisticated manner, they were often smiled at and ignored, or they were politely quieted. At Otter Crest, they had a chance to speak out

Photo by People First

> unashamedly. They were unpolished at first, but the very chance to speak out without others putting a damper on them was like breaking out of prison.

- Discernible patterns of growth have been observed in many of the Oregon participants over the years. Many can even describe personal changes on their own. For example, one young woman with a slight speech impediment described what happened to her:

> I never thought I could get up and speak to others. I was scared I would say something wrong. I used to do some of the darndest things, you see. I got flustered the first time I got up and spoke at the convention, but I got through it and one of the helpers said the people liked me—I was so scared, I wouldn't have known that. Now, I have testified at legislative hearings on group homes and I've spoken on television. I've even talked to two governors, Tom McCall and Bob Straub, about People First and what we are doing.

- The conventions in Oregon have shown an increasing efficiency and sophistication as far as the programs are concerned. The earliest workshops, for example, provided some much needed freedom for persons to speak out. The following year, convention topics dealt with organizational details: "How to Start a People First Chapter in Your Community" . . . "How to Get People to Meetings" . . . "How to Hold Elections" . . . and "How to Raise Money." Today, the conventions are tackling some of the tough current issues in the field: "Barriers to Persons in Wheelchairs" and "How to Get More Service from Your Service Workers," for example. It is obvious from this pattern that members of People First are well on their way to creating a new consumer movement that will, more and more, be heard and reckoned with.
- The People First movement is built more on "moxie" than money. Convention bills have always been paid from the $25 registration fee which each People First member had been saving up for many months in advance. Some agencies do provide assistance—for instance, for transportation costs—but such help comes from budgets that already exist.
- People First members are now on the Governor's Committee for the Handicapped, the NARC Board of Directors and the Oregon State Developmental Disabilities Council. Also, representatives are active on many of the state's task forces that are working on group home standards.
- As members of People First learn to express themselves, it has become obvious that others will need to make shifts in their own attitudes and skills. For example, some professionals visiting both the conventions and the small group chapters have tended to be uncomfortable in some of the meetings. Said one helper: "Some professionals seem edgy in the People First meetings because they always saw themselves as 'bountiful givers' to handicapped people. Now, the handicapped persons' urges to be givers too can clash with those of the professionals. Also, some professionals simply can't stand silence. Some of the members can sit silently and feel their groupness for long periods of time without saying a word, and that's not always bad."
- There is one message which comes repeatedly from People First testimonies that is gathering increasing force: Time and time again, members mention their passionate hate for the word *retarded* when it is used to describe them.

Photo by People First

And so a new consumer force has been born that preaches "self advocacy" and "the power for peer group education." Already, many professionals in the field of mental retardation have been moved by the activities emerging from this group of people who, a few years ago would never have been expected to represent their own interests. But now, some are doing it. And as People First members successfully give us their candid views about current issues in the field, it can lead to fresh insights by us all.

ART EXPRESSION THAT CHANGES PEOPLE'S LIVES

In these days of program technology, mentally retarded persons are often expected to move from Milestone A to Milestone B with professionals X, Y and Z delivering specific interventions according to a program dictated by an interdisciplinary team. Such precise programming has produced benefits. It has, for example, provided documented proof that mentally retarded individuals are developing people—just like the rest of us.

But could there be other creative potentials within some handicapped individuals that the usual technical plan cannot predict? Some people who work with mentally retarded adults have come to believe that there are.

The Alan Short Center, Stockton, California

When this "art college" opened its doors two and a half years ago, it added one more innovative program to the growing list of training options for mentally retarded adults. The program was the result of a crucial need uncovered by another successful California effort: *A Very Special Art Show*. The founder of this art show—who also happens to be the founder of the Alan Short Center—explained what happened:

> In the spring of 1974, special education teachers throughout the state began helping their mentally retarded students to produce all kinds of artistic creations which were shown at Cal-Expo (the State Fairgrounds at Sacramento) in the fall. That year, more than 1000 creations were exhibited. Prizes were awarded and many items were sold. *A Very Special Art Show* was such a success, it has become an annual affair . . . and it's getting better each year. But something began to happen that was painful to us all. Special education teachers wrote and telephoned, saying that many of their most promising artists were turning 21—the age limit for public school attendance in the state—and these teachers were fearful for the future of their graduates. After leaving school, most of these retarded citizens were faced with four options: They would go to an institution, stay at home with no program, attend work activity centers, or enroll in vocational training programs. Many of the teachers were heartsick, because they felt that none of these options would continue the artistic creativity which had been discovered and reinforced in their students. The Alan Short Center was started as an answer to the need these teachers uncovered.

Today, the center is in full operation. Sixty students (ages 18 to 60, with the majority in their 20's and 30's) attend classes in a spacious, 17-room mansion that was once the Stockton State Hospital superintendent's home. The mansion is located on a corner of the institution's grounds in downtown Stockton. Most of the students live in community group homes or in their own homes. However, 25 percent are developmentally disabled residents of Stockton State Hospital who are now in a "community re-entry" program.

The students take a full range of courses in the performing, visual and expressive arts. The current offerings: Drama, Square Dancing, Folk Dancing, Chorus, Instrumental Music (i.e., Swiss hand bells, drums, guitars, recorders and flutes), Music Theory (Many students who cannot read words have learned to read music), Weaving, Sculpture, Pottery Making, Photography, Film Making, Painting, Drawing and Poetry. All courses are extension courses of nearby San Joaquin Delta College and all attending the Center are full-fledged, card-carrying students of the college. The faculty is made up of visual arts instructors, performing arts instructors and music therapy interns.

This private, non-profit agency receives financial support from San Joaquin Delta College which pays for courses on a purchase-of-service basis and from the Valley Mountain Regional Center which covers other service contracts. The remainder of the funds comes from a variety of small government grants and donations.

The energizing force is found in the training process. The director explained, "We're not, as our primary goal, looking for the product. What we're really looking for is the *process* that gets people there. That's what changes people's lives." This process usually is composed of three basic movements: The students create something; they share their creations with their comrades; and the accomplishments are then shared in many different ways with the public. Here are some examples:

Fatso, a musical stage production, has been playing at state fairs, conventions, festivals, colleges and, recently, at the American Theatre Association meeting in New Orleans. The music and lyrics were written by a promising music therapy intern who later became a permanent staff member of the Center. The story line came from the real-life human situations of the handicapped actors themselves. Fatso—dressed in a costume with tremendous amounts of stuffing—is the hero who, at the play's beginning, is ridiculed by the other characters. But Fatso turns the tables. One by one, he calls attention to the deficiencies of the other characters and he tenderly helps each person to accept and compensate for their defects. At the play's end, Fatso comes to grips with his own problem.

The play has been well received, wherever it has been produced. But more important: It has become a powerful force for positive attitude change toward handicapped persons.

The Short Swingers are a fast-stepping, beautifully costumed troupe of precision square dancers. These dancers, who once tended to shuffle just as many retarded persons are expected to do, have performed throughout the state and were recently featured entertainers at the National Parks and Recreation Association's national meeting in Miami. And one singular triumph for the former "shufflers": They now hold workshops and teach non-handicapped persons the various steps.

The students are also active in the field of fine art. Their paintings, drawings, sculpture and photographs are exhibited in colleges and building lobbies throughout northern Califor-

A Scene from "FATSO". Photo by Richard Dreher

nia. Also, the Center has a gallery in the mansion which is open to the public each day.

This steady outpouring of creativity is in stark contrast to the systems managers and training technologists currently in vogue in the field of mental retardation. The contributions of the Center's artists cannot help but keep the field from becoming too ingrown and parochial. The following happenings and concepts show that they have much to give to the field:

- Creative dialogues between artists and technologists began in earnest after some of the West Coast's leading chart-and-graph special education professors attended a performance of *Fatso*. Although technicians and artists often mix like oil and water, the handicapped players in *Fatso* melted the barriers between the special education technologists and the art instructors. As a result, formal plans are now underway to investigate and discuss what is happening in *Fatso*—each contributing what is seen from different perspectives.
- Small groups of students—most classes average from seven to ten students—have discovered a beautiful freedom for discussing and learning from one another while focusing on a common creative effort. For example, the members of one group were so taken with Wonder Woman (featured each week on television) that they decided to construct a life-size, papier mache model of her. The project was a tremendous success. But, while focusing on the careful construction of a woman's body—especially the breasts—the group engaged in a serious and respectful discussion of sex and what it means.
- Applause changes people. This is as true for the handicapped students at The Alan Short Center as it is for any professional performer. The cast of *Fatso* now struggle to improve their stage presence, diction and grooming. The actresses decided to go on a rigid diet to prepare for their New Orleans performance; and all of the performers have developed an excellent sense of timing when the audience laughs.
- The faculty wisely recognizes that all mentally retarded persons will not become enthused in such a setting as this. For this reason, candidates are invited to come to the Center and spend time there to see if they really want to enroll. Even if a student fails to thrive in the setting, faculty members skillfully—and without causing guilt feelings—manage lateral transitions to other programs in the community.
- For many students, certain perceived limits have been dissolved. "These people came to the Center with a long history of being told verbally and nonverbally what they can't do," the director stated. "And they all came to the Center labelled 'mentally retarded,' while their records stated they have IQ ranges of from 20 to 70. They were often called 'behavior disordered,' too. But when these people were put into settings where there are no limits, some have gotten so enthused with what they are doing that they surprise everybody. They transcend the limits that others have placed on them." The director of *Fatso* explained, "I never show them I expect the best, or even the most. I just help them along in the process, and they have moved on their own, far beyond anything I ever expected."
- Such freedom to move in their own creative directions has given them confidence to move in new directions beyond the Center. Such moves usually begin with questions they had always been afraid to ask. For example, one man asked, "Why can't I work at McDonald's?" The only answers he received were: "Why not?" Today, he holds down a job at McDonald's and loves what he's doing. Other students who, two short years ago, would never have thought of getting involved in academic learning have transferred to the Delta College campus where they are taking special courses in simple reading and math. They are doing it because they were counseled to try it. They are doing it because they want to.

Such success stories have not gone unnoticed. The National Committee, Arts for the Handicapped in Washington, D.C., has named The Alan Short Center as one of its "National Model Sites."

The Center has made a reality of the statement by Mark Twain that "We are only handicapped with what we think we cannot do." Many of the faculty members have adopted the statement as their unofficial motto. But even those who haven't seem convinced that soaring expressions of poetry, the inner eye of beauty and fresh, clear utterances about what it means to walk as a human being can come from persons labelled "mentally retarded." Nothing that has taken place at The Alan Short Center has lessened their conviction.

The Mentally Retarded Offender

BECOMING SOMEBODY . . . THE CONSTRUCTIVE WAY

When a mentally retarded person has been found guilty of breaking the law, the judge is often faced with two equally grim alternatives. If the handicapped offender is sent to prison, he often becomes the vulnerable "patsy" who is cruelly used and led astray by the other inmates. However, if he is sent to an institution, he is usually "streetwise" enough to become a ringleader who manipulates other residents into committing antisocial acts.

Five years ago, one counselor in Nashville described the youthful retarded offender's plight when he testified, "The boys we get just don't fit anybody's program. The schools don't want them. The MR institutions don't want them. The training schools don't want them. Their neighborhoods don't want them." Fortunately such testimony has become a cause for concern in states like Tennessee, where there is a general feeling that the mentally retarded offender should no longer be ignored.

Our House Two, Nashville, Tennessee.

One young man came to the home ready to fight anybody who opposed him. Another arrived telling everyone that someday he would be a successful, well-dressed, big-car-owning pimp who would sit back while "his women" worked for him. A shy youth came, thinking that the best way to live was to quietly steal things. Others came, hating teachers, policemen and all other authorities who had attempted to straighten them out in the old environment. But behind the anti-social attitudes of the eight teenagers (ranging in age from 15 to 18) could be found some piteous common denominators: They were all mentally retarded . . . they were only pseudo-streetwise . . . life was a painful puzzle to them . . . and they were trying desperately—in the only ways they knew how—to be somebody.

The hand-picked staff members of the home understand such facades—and the internal anguish, too—and they begin to involve each young man in a series of activities designed to help him be the "somebody" he really desires. But they do it in constructive ways.

Our House Two is one of four homes based upon information gained from an earlier demonstration effort (The Juvenile Offender Project, a joint venture of the Tennessee Department of Corrections and the John F. Kennedy Center of Peabody College) and mandated by recent state legislative action (The Special Correction and Rehabilitation Act of 1974). Similar youth programs are operating in Memphis (The Tennessee Law Enforcement Planning Agency (TLEPA) Group Home) and Cleveland (The Hermes Group Home for the Mentally Retarded Offender), while one unit serves ten adults in Knoxville (The Sertoma Learning Center).

Our House Two is located on 12 acres of land facing a suburban highway and a large shopping center. Behind the house is farmland. Consequently, the home is not as noticeable as it would be on a city block in the center of town and the clients have easy access to both the rural and urban ways of life.

Also behind the house is a small cottage which is used as a remedial education classroom. The courses delivered in this cottage school are designed to help clients find happiness in learning—to the point where they will eventually want to return to a public school.

All clients are first sent by the court to Clover Bottom Developmental Center. This institution then refers them to Our House Two, remaining involved by assisting with the diagnosis and evaluation and by offering other supportive resources as needed.

Since these mentally retarded offenders are on the brink of adulthood, the home becomes a much needed transition stage where a handicapped person is helped out of his childhood environment and prepared to move into a community of his own choosing as an independent, responsible, productive citizen. Our House Two, providing love and technological reinforcements, offers a retarded offender the richest opportunity he will ever have to change the direction of his life.

The atmosphere is dignifying and low key. The basic training strategy can be stated in four simple sentences which are connected with an easy-to-remember mnemonic—RAID:

Rules should be simple and as few as possible.

Approve appropriate behavior promptly.

Ignore inappropriate behavior while in action.

Disapprove or interrupt dangerous and destructive behavior.

Many nurturing activities have evolved from the above basic strategy. For example:

A thorough individual program planning process that utilizes the Gunzburg Progress Assessment Chart (PAC) system and all components of the AC MRDD Standards is developed for each resident. Those who participate in the process are the client himself, home staff members, the client's parents or other relatives and representatives from the public school, the local mental health agency and Clover Bottom Developmental Center.

Every new resident receives at least four hours per day of personalized remedial education in the cottage classroom until he re-enters public school special education classes. Even after this happens, the resident will still receive two hours per day of such remedial work. The teacher/counselor who conducts the session is skilled at building success into every remedial assignment. For example, when it was learned that Robert could read 30 words, the teacher/counselor composed a story containing only those words. On the day that Robert read this story to his fellow residents, they cheered as he beamed with pride. Robert's love of learning was born that day. Six months later, he was able to read over 200 words.

The housekeeping of Our House Two is a matter of good teamwork and timing. Everyone has specific chores to perform for which he receives points that can be saved and used for personal rewards. The young men are even responsible for breakfast, with each resident taking his turn as cook, table setter, dishwasher and kitchen cleaner.

Every resident has at least one formal hour of individual couseling per week with either the teacher/counselor or the administrator/counselor. However, all house staff members are available for many hours of informal guidance sessions. The complete milieu of Our House Two demonstrates to the residents that in this home all are advocates who stand ready to inspire and reinforce as many positive changes in each resident as possible.

Self-government meetings were started with some apprehension, but have now produced creative results beyond everyone's expectations. Utilizing a rotating chairmanship and *Robert's Rules of Order*, the residents review and revise all general rules of the house. They also modify and administer each resident's individualized point and reward systems. For example, Richard was found guilty of staying up late and playing TV too loudly. It was agreed that Richard would be fined a certain number of points for each late night TV disturbance. The loss of these points would make it impossible for him to receive his most prized reward: a date with his girlfriend on the weekend. (No staff member would have dreamed of being as strict as Richard's fellow residents.) Consequently, Richard became remarkably quiet in the evenings.

Options for work, education and recreation in the community have become so numerous that most residents have a problem deciding what they will do. Some recent examples of summer activities: Richard and Robert had jobs working on house rehabilitation crews serving elderly persons . . . Sam worked as a groundskeeper at Peabody College . . . Carl, being atheletically inclined, participated in Tennessee State University's summer athletic program (the same program that Olympic champion Wilma Rudolph participated in as a young girl) . . . Pete attended a center that taught small engine repair . . . Jerome took guitar lessons . . . and Leon and Lester, the two youngest residents, enrolled in the Nashville Parks and Recreation Department summer program.

Although Our House Two has only been open since December 23, 1977, three clients have already moved on. Sam, Richard and Robert have kept their jobs and have moved into "sheltered apartments." (Our House Two is but one of a network of community residences developed by Home Two Incorporated, a private, non-profit agency. It is expected that residents will move into other segments of the network.) All but one of the remaining residents are attending public high school while getting extra booster education in the remedial classroom. Three new residents now fill the vacancies left by those moving out.

The activities in Our House Two and the documented development of its residents show what can happen when a state becomes concerned with the plight of its mentally retarded offenders. Tennessee is one state among many which is now committed to helping such handicapped persons to be somebody—and to do it constructively.

THE SCHOOL THAT FINDS ITS STUDENTS ON THE STREETS

An increasing number of teenagers in large cities have found their school education so distasteful that they no longer attend. Instead, these fugitives from the classroom receive a different kind of education on the streets: how to evade the authorities and how to counteract long hours of boredom by engaging in illegal and destructive activities. Many of these drop-outs are mentally retarded teenagers who desperately need every practical educational opportunity they can get in order to survive in a world that—without warning—can overwhelm them at any time.

As long as these retarded teenagers are on the street, they remain invisible. However, they are frequently brought to court for crimes they have committed (all too often in a bungling, unsophisticated manner). Once in court, they receive the label "mentally retarded offender," which only makes matters worse, since it is unclear whose responsibility it is to serve them. One official from a large Eastern city stated that, in the past ten months, he attended five conferences at which agency representatives tried to determine whether these handicapped offenders were the responsibility of the public schools, the youth authorities, the developmental disabilities agencies, the juvenile court system or the agencies which deal with child neglect.

Meanwhile, some agencies like New York City's Association for the Help of Retarded Children (AHRC) are not waiting for official decisions to be made. Since they are used to serving mentally retarded persons with unmet needs, they have quickly moved into the business of educating these handicapped children of the streets.

The Flushing School, Queens, New York

It is not uncommon for a staff member of this school to enter a private home, walk into the bedroom and persuade a student to get up and come to school. Such an action is only one of the many ways these teachers demonstrate two basic attitudes of the school. First, these teachers really care about what happens to their students and they show it, not by what they say—words like "love" and "care" only provoke immediate suspicion in the teenagers—but by the many out-of-the-ordinary things they do. Second, these teachers believe that learning is an extremely rich experience.

Neither of these two basic attitudes are particularly easy to get across, since the students have grown up hating schools and teachers. And yet, it is these two attitudes which eventually draw a student into faithfully attending The Flushing School. These attitudes are genuine. They have to be, since a student who has reason to doubt their genuineness can "blow" his chances for education on the spot.

Flushing School is a small, personalized school that holds classes in a rented church building. The program accommodates 20 young men, from 13 to 18 years of age, who live in various parts of the Borough of Queens in New York City. The program came into being two years ago when AHRC and the Developmental Disabilities Council of New York began discussing the plight of these teenagers and decided to develop this pioneering program.

The staff members are a sensitive, committed group of professionals who live in the area and who possess a keen street wisdom themselves. Each staff member seems to have a personality that is attractive to students like these. ("These guys will push you to the wall to see if you can be strong and kind at the same time. This is no place for 'softies'.")

The program is so closely tuned to the practical needs of the students that many vivid, relevant educational components have been created out of the sheer necessity of giving students exactly what they need. For example:

- The staff and students begin by having breakfast—or, perhaps, a cup of cocoa—together. Since many of the students do not receive breakfast at home, this coming together is a must. It is, everyone agrees, an excellent way to begin the day.
- After breakfast, the male staff and the students meet in the lavatory for on-the-spot training in grooming. They practice such things as washing their hands and face, brushing their teeth, combing their hair, and applying deoderant.
- No weapons are allowed. In the first days, all knives, chains, pipes, large bolts, whatever, were checked when the students entered school and were returned when they left. Later staff members decided to give advance announcement of a change of policy: Any weapon brought to school would be taken away and never returned. After some testing, the procedure was accepted by everyone.
- Press statements and publicity about the program are rarely allowed in order to respect the confidentially of the students. The on-site visit and interviews that produced this report were approved only after it was made clear that the readers might be able to use the ideas created at The Flushing

School in similar programs elsewhere.

- The label "retarded" is never used in conversations at the school. Almost all students have developed a natural hate for the term.
- An advocate is present on the staff who automatically goes to court with every young man in trouble with the law. The advocate also keeps communications channels open with all probation officers and assists with teaching duties.
- An interesting data-based program was utilized in the opening days of the school in order to stop two negative behaviors (fighting and running in and out of the room) and to reinforce one positive action (participation in class activities). Substantial rewards—cameras and boxing gloves, for example—were awarded when students achieved the stated goals. Later, classes became so orderly and the interest of students became so high, that this component was no longer needed.
- Three basic foundation courses have been instituted for all students: Workshop, Art and Academic Education. The workshop became the earliest interest-getter. Each student was helped to build a bicycle from junk parts. When the bicycles were completed, they became the students' property to take home. Recently, the students constructed their own paddle ball racket for a special tournament they were having. They have also been doing detailed woodcarvings of animals on plaques. All products must have a practical relevance for the student and all products are theirs to keep. During such processes, by the way, the students learn to use a wide range of heavy-duty (even dangerous) industrial tools.

After initial successes in the workshop, the students became involved in art. It was learned through the students' drawings that many had serious problems in how they saw themselves and how they saw the world around them. The school's art teacher was effective in helping the students correct faulty perceptions and do complete, dignified drawings of themselves and others around them. There is some evidence that the overcoming of some of these distorted views may have paved the way for improved reading ability.

The academic class was the last of the three foundation courses to win the students' interest. It was learned that many students were secretly ashamed of being unable to read and write and that they longed to posses such skills. When the academic teacher enabled each student to achieve real success in personalized reading tasks, their interest in academic pursuits began to increase. However, even in the academic class, such activities as reading, writing, math and social studies have extremely practical goals—like learning to read the newspaper for meaning and learning to fill out working papers.

Learning all aspects of cooking is another component of the school. Each day, two students and a teacher decide on the menu for a noon meal to be eaten by all staff and students. Together, they purchase the items, cook them, set the tables and clean up after the meal.

On warm spring days, students and teachers form crews that spend half the day in the community making real money which students can keep. The crews have seeded and cut lawns, planted gardens, tarred roofs and repaired automobiles. On snowy days in the winter, class schedules are modified in order for small crews to make money by shoveling walks.

A tremendous number of "domestic science" trips take place in small groups. Many students have gone with their art teacher to Manhattan museums ("Who would have thought these youngsters would learn to appreciate art?) Many of the students had never before travelled over the bridge to Manhattan; however, now they go sightseeing everywhere. Other trips that are purely practical include going to the post office to purchase stamps and mail letters, visiting health clinics and talking to personnel officers about how to apply for jobs.

Although the overall Individualized Education Plan (IEP) is developed, carried out and measured according to high standards, each student receives a daily personalized IEP schedule when he arrives each morning. The schedule carefully spells out all activities a student will attend along with the exact time of arrival. Such a schedule is excellent training for the student, and it keeps the staff members, who write them, on their toes as well.

Each student has a *confidant* in one of the staff members. All staff members are trained for such a role. The fact that each student has someone to whom he can go and discuss in confidence anything that is bothering him, is one more comforting factor that makes retarded offenders want to be part of this school.

By this time next year, many new educational components will probably have been adopted by The Flushing School, replacing other components which have outlived their usefulness. Such is the strong, flexible nature of the school. But no matter what changes are instituted, the education will continue to be down-to-earth and practical. The size of the school will, in all probability, also continue. The staff is well aware that the school's smallness, intimacy and comradeship are keys to the program's success.

There is one precious component that is central in every activity: the way that staff members help students *feel* their genuine success. One teacher made it clear why these students need such feelings of accomplishment: "These fellows have known one failure after another all of their lives. When they do something good here—I mean really good, not just a put-on good—how proud they are. They want more experiences like that. It's like a hunger with them."

Mental Health

THEY TACKLE LIMITS AND DISTURBANCES AT THE SAME TIME

Being mentally retarded is bad enough; being mentally ill, too, makes it many times worse. It's not just that such double afflictions are difficult to treat. The sad but undeniable fact is that adequate treatment is extemely hard to come by; psychiatric professionals in the United States often refuse to work with mentally retarded persons; and mental retardation professionals often ignore deeper emotional disturbances which may be present in their clients. The end result is that mentally retarded persons who suffer from psychiatric disturbances are frequently caught in the middle—a middle where all the needed services simply don't exist.

The Rock Creek Foundation for Mental Health, Bethesda, Maryland

The psychiatrist/director of this psychiatric day treatment program for mentally retarded persons explained why such handicapped people are not the most desirable clients for psychotherapy:

> Most psychiatrists are bright individuals and they like to work with other bright persons who can become more like their psychotherapists. For this reason, those having high achievement levels—like medical students—are preferred patients. But when a mentally retarded person comes for psychotherapy, he is quickly "referred away." Such referrals are polite diversions, so the psychiatrist doesn't have to say what he really feels: "Get out of my office . . . I don't want to talk to you . . . I don't want to recognize that you have feelings, too." Of course, a retarded person will never develop like a medical student can, but that handicapped person can be helped to find an emotional stability and a career within his range that's every bit as satisfying. Unfortunately, most psychiatrists fail to see value in such an opportunity.

An administrator, who was trained in public health administration, then described the usual predicament of the men and women who are served in this agency:

> Many of these people have needed psychiatric intervention almost all of their lives, but such needs were ignored. As young children, their aberrant behaviors were ascribed to mental retardation syndromes. During adolescence—when most attended special education classes—their bizarre actions were tolerated just as long as such acts were not sexual or violent. For example, one young lady literally believed she was Cinderella, but none of her special ed teachers did anything about it. The real shock comes after these disturbed persons leave the special education classes. Then, they are rejected by one adult program after another. When this happens the families are forced to keep their disturbed children in the home with no programs or to send them to an institution. That's a bitter set of alternatives to face after at least 20 years of hard work and sacrifice.

It was frequent situations like these that motivated the director and administrator to establish the non-profit Rock Creek Foundation for Mental Health in 1973. Today, 33 young adults who, for the most part, are mildly and moderately retarded and who have severe emotional disturbances, travel each weekday to this day treatment center located on the second floor of a building in downtown Bethesda.

At the Foundation, the young adults engage in 40 hours a week of activities that utilize both the latest behavior methods from the developmental disabilities' field and the best expressive techniques employed in psychiatric settings. This private, J.C.A.H.-accredited facility gets much of its avant garde character from a number of programmatic twists not usually found in day programs for mentally retarded persons:

- There are no separate staff and client lounges, washrooms and general activity areas. Instead, a spirit of togetherness is fostered in all daily activities. For example, staff and clients are encouraged to make friends with each other, even to the point of lunching or shopping together during their free periods.
- Mealtime programs are nonexistent at the agency. Staff and clients go to various restaurants and fast food facilities in downtown Bethesda, or they "brown bag" it together.
- The agency has no transportation facilities of its own. Clients come to the center from all parts of the Greater Washington, D.C. area via public transportation which they are trained to use.
- No one-way vision mirrors (allowing the staff to secretly watch clients) can be found anywhere in the facility. Explained the administrator: "With the staff-client equality we are fostering, one-way vision mirrors would be unfair."

Mental Health

- The neighborhood has become an extension of the treatment team. Many of the people who work in the local businesses know the Rock Creek staff and clients on a first-name basis. In fact, one fast-food facility trains new counter employees to recognize the capabilities and limitations of Rock Creek's clients (e.g., "Make sure that John shows you his money before he orders." . . . "Sam has just learned to count out the proper change for his hamburger and shake, so wait until he does it correctly.")
- Every staff member is considered a therapist. Although Rock Creek has a rich staffing pattern (including psychiatrists, psychologists, psychiatric social workers and nurses, special education teachers, mental health workers and vocational training personnel), even the secretaries, receptionists and bookkeepers are expected to provide significant relationships with clients who seek them out. Front office personnel even take part in program activities from time to time.

The rationale for providing only day care treatment is that such a procedure allows the client to make the most of his or her active weekday hours. There are other advantages: Ties between the client, the family and the home community are not severed; there is no need to add staff and facilities to provide 24-hour care; and the cost of therapeutic care is reduced.

The ultimate goal of all therapeutic and developmental endeavors is to help clients qualify for jobs or volunteer work that provides dignity to the client. "We cannot over-emphasize the importance of independent living skills—particularly work," the director stated. "How often have we been to parties where the second question asked is, 'What do you do?' Since so much self-esteem is tied up in the answer to this question, we intend to help our clients develop such meaningful vocational skills that they'll be able to answer that second question proudly."

The programs at Rock Creek Foundation consist of many carefully executed treatment modalities for specific emotional disturbances in mentally retarded persons. Some examples of programming follow:

- *Individual Therapy.* Conventional psychotherapy techniques are used to help clients understand and deal with specific disturbances, and all psychotherapy programs are designed to treat specific illnesses. Most sessions are from 30 minutes to one hour long and are held three times a week. In some cases, 15-minute sessions are conducted with greater frequency.
- *Group Therapy.* Male and female co-therapists conduct group sessions daily. No group contains more than eight clients and all interactions are focused on a here-and-now orientation.
- *Family Therapies.* A flexible approach to family relationships is developed which covers all group and individual styles. Over 85 percent of the clients are involved in some form of family therapy.
- *Community Meetings.* All staff and clients meet together for at least 30 minutes each day. At these meetings, successful achievements of both clients and staff members are recognized and praised; planned and emergency absences are discussed; and problems are aired (anyone in the "community" can bring up a problem that seems pressing). Since the atmosphere is one of mutual sharing, the community meeting contributes greatly to the treatment process by reducing feelings of isolation and futility.
- *Structured Activity Groups.* Art therapy, dance therapy, psychodrama and occupational therapy are used to help severely disturbed clients express themselves in ways they've never been able to do before.
- *Task Oriented Groups.* As disturbances are diminished, clients are channeled into small, time-limited groups that pursue single educational or service goals. Specific aspects of such things as sexuality and money management are explored; current events described in the newspaper are explored in depth. Since the groups travel for the data they need, the Greater Washington area becomes their "classroom."
- *Vocational Program Ladder.* Since psychiatric disturbance can be extremely "expensive," sapping much time and energy from a client, there is often a need to "replenish" the client. The Rock Creek staff does it with *real work.* The process begins in the center itself when clients are paid the minimum wage to successfully complete daily chores like maintaining the coffee urn, vacuuming the floor or emptying the wastebaskets. From this first, successful taste of work, the clients (none of whom have ever held a job before) are helped through an exacting, step-by-step process that ends with either full-time employment or volunteer work that, in the client's view, gives a sense of dignity and achievement. Small career exploration groups travel to industrial settings to observe people at work, ask questions about working conditions and find out how to qualify for a job in such a setting.

Later, these clients move into the community as members of small, part-time work crews. These crews tackle jobs like cleaning the hallways and stairwells in a 15-building apartment complex. In all cases, the work must be real work in the community, with the minimum wage received. Still later, vocational staff members place clients in supervised part-time work stations in Federal government agencies and service industries in the Greater Washington area. Since the Federal government has many serious training and placement programs for handicapped persons, many of the Rock Creek clients are eventually given "700 hour probationary placements," which can lead to successful full-time government employment. (The U.S. Government has been the unsung leader in the nation in the hiring of handicapped persons.)

Throughout the carefully graduated vocational process, both vocational counselors and therapy staff members perform a detailed number of follow-along functions, supporting the client and reinforcing his or her progress even after full-time employment is achieved.

A PROGRAM THAT MAKES THERAPISTS OUT OF PARENTS

Most Americans cannot imagine what it would be like to have a four-year-old child who ran through the house destroying everything that was breakable . . . screamed almost incessantly . . . climbed on top of the kitchen cabinets . . . fell to the floor in a tantrum every time he was touched . . . threw his food . . . hit, bit and kicked his brothers and sisters . . .

There are always easy assumptions that can be made to explain such behavior: "The parents are soft," for example, or "All the kid needs is a good spanking." But what if the assumptions don't apply? In this particular case, the parents—Philip and Mary Sanders—were far from being soft; in fact, they had already raised three well-adjusted children who had never behaved so destructively. And they had tried spanking, but such punishment only increased this pathetic, tiny tornado's rate of destruction.

A mother of another child with similar behavior explained what it was like:

> Here you are, out in your little neighborhood, in your little house, and you look around your neighborhood and you look down the street, and there's *nobody* out there you can even talk to about your child, because they don't understand . . . And that's kind of hard, too . . . It's a very lonely feeling, especially for people who don't get the help they need when they need it.

Regional Intervention Program (RIP), Nashville, Tennessee

This treatment center has no shortage of persons who can help families with "behaviorally disordered" and "developmentally delayed" preschoolers. There's no waiting list either. Help begins almost immediately after a battle-weary parent contacts the program. It is a very special kind of help, for not only are the many therapists well trained—*they, too, are parents of children with the same problems.* (In the entire program, there are only six master's-level professionals and they serve only as "resource persons.")

Since 1969, a total of 420 families have received help from RIP. Each treatment target is, of course, individual; however, the treatment sequences follow a general pattern. Here, for example, is what happened to Philip and Mary Sanders and their son, Jamie:

It began on Monday morning, a year and a half ago, when a thoroughly exhausted Mary Sanders and Jamie kept an appointment with their pediatrician. The physician mentioned a film presentation he had seen, describing RIP, and suggested that Mrs. Sanders call to see if Jamie could be helped by the program. She called within the hour.

On the following Wednesday, Mrs. Sanders attended an intake conference at RIP which was conducted by a trained parent who skillfully handled 14 checklists, authorizations and negotiations. Included in the issues which were discussed was a "parent participation" agreement. After it was thoroughly explained, Mary Sanders signed an agreement that she would: (1) appear with Jamie for each session (every weekday morning for more than a year) and take primary responsibility for her son's treatment as recommended by RIP staff members; (2) pay no fees, with the understanding that continuance in the program depended upon her work in relation to Jamie and the program as a whole; and (3) receive support from parents and, in a short time, give support to new parents. She also agreed to "pay back" the program with six months' daily service after Jamie's treatment was completed. As the intake conference was concluded, Mrs. Sanders was assigned a "parent case manager" and a "support parent" and was told that treatment would begin at RIP in two days.

On the first day at RIP, Mrs. Sanders and Jamie were asked to spend 20 minutes in the "generalization training room," a simulated three-room apartment—living room, bedroom and kitchen—where she and her son were instructed to play with a specific number of toys, on cue, while two parent observers and the case manager watched through a one-way vision mirror and systematically recorded what was happening.

As soon as the session began, Jamie's behavior became violent: toys hurtled through the air—some struck the mother. The session was stopped abruptly with the mother in tears. ("I guess they couldn't stand seeing a four-year-old beating up his mother," Mrs. Sanders said some months later.) Immediately, the observers and the mother went into a "feedback session," in which the mother was supported and specific acts were discussed. Mrs. Sanders

A RIP parent learns to manage her child's behavior while two "veteran" mothers record her progress through a two-way mirror.

and Jamie were than scheduled for another generalization training session on the following Monday.

During the weekend, Mary and Philip Sanders received a visit from their "support parent," who was placed on-call to the Sanders at any time, day or night, during Jamie's treatment period. In the next month, no fewer than 15 telephone conversations took place between the family and their support parent. Although the conversations primarily provided much needed emotional support, technical advice was given as well. For example, the support parent advised the Sanders on how to make their home "childproof" by storing breakable items and installing gates and barriers. The support parent also helped the family develop in-home programs having to do with Jamie's mealtime and night time behaviors.

On the next Monday—and on the days following—the generalization training and feedback sessions were continued. From these sessions, it was learned that everybody had been unwittingly reinforcing Jamie's violent acts by giving him extra attention when he committed them. With this knowledge, the mother and child began a long series of regular sessions called "individual tutoring." Again, the case manager and parent observers first watched the sessions and joined Mrs. Sanders in feedback, helping her develop skills that could turn off bad behavior and turn on good behavior. Jamie also spent time in an intake classroom, where his developing healthy behavior was reinforced in a group setting.

After a year of hard work by the therapists and the entire Sanders family, Jamie began to progress dramatically. His violent acts were diminished and the childproofing devices were removed from his home. At RIP, Jamie was promoted to a "language/community" class for handicapped children and normal children who served as models. (Since the normal children who attend this class are the brothers and sisters of the handicapped child, the arrangement relieves parents from the added expense of day-care.)

This fall, Jamie is attending a public school. His entry into a special education class was assisted by well-trained parents who serve as "liaison workers." They set up meetings with public school faculty members at which they described Jamie's progress at RIP and his immediate program needs. In Jamie's first month at school, the liaison workers made three follow-up visits to the school on the child's behalf and remain available as advocates should such services be needed.

Since RIP is a dynamic program that changes as the needs of the handicapped child and his family change, the Sanders' experience makes visible only the tip of a rich program that contains many basic concepts which have been shaped through the years. Some examples:

- An efficient, three-level organization keeps RIP cohesive and flexible at the same time. On the first level, all on-line service delivery functions are carried out by parents. On the second level, the six professional resource persons serve as a back-up force. The third level is a seven-member Evaluation Committee of parents and community professionals—elected by the parents—who monitor all treatment activities and report monthly to the Tennessee Department of Mental Health and Mental Retardation.
- The parent-child relationship is the heart of the program. Every program component is constantly adjusted so that optimum success can be realized in this single, crucial relationship.

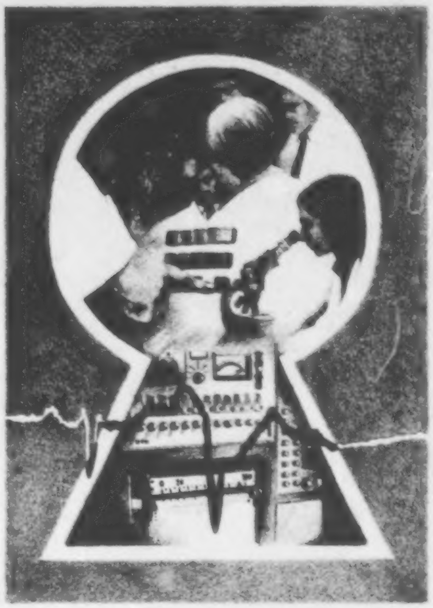
- Intense parent participation keeps the program dynamic. One professional explained why: "Professional agencies simply cannot shift as rapidly. Pro's spend time and energy, each developing his own professional role which 'locks' the agency into a more constant, unchanging service pattern. The only thing that's constant at RIP is that parents will always deliver the on-line therapies."
- A management-by-objectives system keeps RIP remarkably accountable. For example, "targets that are time-bound, numerically delineated measures incorporating predetermined sequential activities" are written for each family-child relationship. These targets are evaluated every six months. Then, by using a unique point system, an account of targets made and not made is passed to the Evaluation Committee which, in turn, produces overall reports for state officials. The major targets for the complete program are rewritten each year by the Evaluation Committee.
- RIP is flexibly data-based. Careful measurement of input-process-output variables are utilized in all program operations. However, while some data-based programs perfect a single, rigid system, RIP has developed better than 25 different types of change-producing systems. Always, such flexibility is determined by the specific needs of each family.
- There are no fees. While the state pays the operating costs (less than $10,000 per year), the parent payback plan (a minimum of nine hours per week for six months) has kept RIP remarkably cost-efficient. Over the years, only 15 percent of the enrolled families failed to pay back their obligations; and many of these parents were officially released from the obligation because of family tragedies or hardship.
- A complex system of detailed tasks are performed by parents. They serve as intake workers, support parents, case managers and liaison workers. They are also teachers, assistant teachers and clerical workers. One parent is even trained as a video camera operator who periodically videotapes parent-child interactions.
- A back-up network of six consultants who are in private practice or attached to outside agencies are available on an as-needed basis in the areas of pediatrics, psychiatry, child psychology, special education, child development and speech pathology.
- The Nashville Junior League provides a number of valuable volunteer services to RIP. For example, the League offers rent-free program space (they own the building), supplies volunteers, conducts fund-raising drives, sponsors holiday parties and provides emergency funding for needs like special shoes and prosthetic devices and for families with financial hardships.
- The use of siblings as models has been invaluable in helping handicapped children acquire appropriate social and language skills. Also, the siblings receive a richer education than they would have received in an ordinary day care center.
- RIP training is seen as "rehearsal training." Successes in the training setting are minimized. At best, it's only a boot camp setting where families and handicapped children are prepared for life in the real world. The real test of RIP's success takes place in such settings as the home, the grocery store, the restaurant and the public school.

On February 28, 1974, the Tennessee Legislature passed a resolution calling for the statewide expansion of RIP. With this mandate, a RIP expansion team has worked with area mental health centers throughout the state, helping start programs and giving intensive, competency-based training courses for staff members. In addition, the RIP expansion teams have—by invitation—assisted in setting up new programs in West Hartford, Connecticut, Cleveland, Ohio; and Branford, Ontario. More expansion projects are being planned.

RIP demonstrates that when the service is clear, when all tasks in delivering the service are broken down into many different jobs (with exact procedures, targets and time limits) and when every task is kept under the scrutiny of evaluators, a striking thing can happen: A cadre of parents with a special need to excell may—in some settings—become more motivated and efficient therapists than professionals.

The "bullpen" office arrangement at RIP promotes constant exchange of ideas among parents and staff.

Prevention



THE OTHER SIDE OF A DIVIDED HOUSE

An unfortunate myopia is present in some who work in the field of mental retardation. Sometimes, those who help citizens overcome or compensate for mental retardation have little knowledge of two other large groups who are working to prevent such handicaps from occurring in the first place. One group is working on biomedical prevention, while the other struggles against environmental deprivations caused by low income and sociocultural problems. When the three groups operate independently of one another, the field becomes a divided house.

It is admirable that workers in all sections of the house can be so enthusiastic about their own human service efforts that they have little time for other pursuits. But it is counterproductive when experts in a midwest community-based service are found to be completely ignorant of a biomedical breakthrough that took place in a medical school ten blocks away.

It is also counterproductive when trainers skillfully deliver services to retarded clients, but remain oblivious to the painful economic and cultural barriers that encircle the home and neighborhood from which they come. Of course, this cannot be said about Project FIND, the South Bronx Development Services Team, and many other broad-based services that this report describes. But when it happens, money and manpower are wasted.

Although this report deals with programmatic efforts on behalf of mentally retarded persons, it would be wrong to end it without providing the reader with a brief look at the other side of the house—into the world of prevention that is every bit as challenging.

Prevention Options: Everywhere, U.S.A.

If we, the American people, could marshal all we presently know about preventing mental retardation, and if we could organize and carry out all of the options available to us, one dazzling achievement would emerge immediately: *We would reduce the incidence of mental retardation by one-half.*

In purely economic terms, the annual savings to the American people would be enormous. Last year, for example, California alone spent $900 million on the care of its mentally retarded citizens, and this was only one of 50 state outlays for that purpose. But even more important than the savings in dollars and cents is the saving in human lives. How much would we add to human dignity and how much would we subtract from human suffering were we to cut mental retardation in half? We can only guess. However, guessing remains a poor substitute for actually carrying out the options presently available to us.

The following list of options is the result of structured conversations with a number of prevention experts situated across the nation. The list is by no means complete, and others involved in prevention efforts could make many additions.

■ *The Ideal Time for Child Bearing.* Today, there is sufficient evidence to show that the incidence of disability rises sharply with mothers under 20 and with those over 35.

Many younger mothers—especially teenagers—are not emotionally, socially, economically nor biologically as prepared as they could be at a later age. According to Dr. Richard Koch, Professor of Pediatrics, The University of Southern California:

> Quite often with very young mothers, the pregnancy has caught them by surprise. They sometimes tend to hide their condition until it shows. By then, they are four to five months long. They haven't readied themselves physically, paying little attention to nutrition and a wide range of options that could have insured the best possible health for their child. For example, they have not had sufficient checkups and they often are without immunizations that could protect them from such diseases as German Measles (rubella) . . . Many just aren't ready. Their biological systems may not have matured as fully as possible for the task. And having a baby costs money . . . economic deprivation introduces disabling factors as well.

On the other hand, many congenital anomalies begin to increase along with the age of the older mother. Chromosomes can fail to function properly. Mothers who have had many previous children may develop impairments in their childbearing systems. Even a woman of 38 who has had no children may have developed solidification in the bones so that there is less resiliency in the pelvis. When such things occur, problems in childbirth begin to rise.

■ *Health Planning Before Conception.* We have entered an age when pregnancy need no longer catch us by surprise. The conception of a child can be a purposeful, carefully planned act, one which takes into account a series of crucial health checks and functions.

Quite possibly, some impediments to such a purposeful process can be traced to older fathers and mothers who, only a few short years ago, did not have all the backup health services available to their sons and daughters. As a result, older parents have not always educated their children regarding the many relatively easy health checks and functions now available.

■ *Care of the Unborn Child.* Almost all of the workers involved in prevention pursuits seem agreed on one point: Americans must raise their consciousness about protecting the fetus in the mother. Researchers have come to see that the fetus is many times more vulnerable to infection and trauma and in need of more proper nutrition than anyone dreamed was possible 20 years ago. For example, excessive drinking of alcohol during pregnancy has a marked effect on the fetus. Some researchers, in fact, now believe that alcohol is one of the most common cause of defects in the fetus leading to mental retardation. Also, studies now show that smoking can result in decreased birth weights. One physician felt that the warning on cigarettes should be modified to read, “Warning: The Surgeon General has determined that cigarette smoking is dangerous to your health and *especially to children in a mother's womb.*” He felt that a similar warning should be placed on bottles of liquor and he wished that the liquor industry, out of concern for the children of the nation, would initiate such a warning voluntarily.

One of the stongest indicators that the fetus needs extraordinary protection and care stems from recent studies which, according to Dr. Robert Cooke, President of the Medical College of Pennsylvania, “show that when a woman believes she is pregnant and the earlier the pregnancy is confirmed . . . and the earlier she can embark on adequate pre-natal care, the lower will be the frequency of abnormality.”

■ *Anticipating “At Risk” Situations.* The day is coming when a mother-to-be showing even the slightest problem in either her own or her unborn child's functioning could automatically be transferred to a regional unit possessing a comprehensive array of the latest equipment and services for solving such potential “at risk” situations. Such a service would take the pressure off local health units to purchase expensive equipment and retain professional services they seldom use. The benefits would be twofold: for the local unit, a great reduction in the average per-patient cost; for the mother and infant, a thorough monitoring and intervention from the moment trouble is diagnosed, during the birth itself and extending throughout the crucial post-natal period.

“The mother is the best incubator any infant can ever have,” Dr. Cook stated. “The transportating of a child in the uterus to such a specialized monitoring and maternity unit is so much better than the old practice, where the local physician and the hospital staff blindly hope for the best until the baby is born disabled and it is transferred to a regional unit after the fact.”

■ *Genetic Counseling.* Today, it is possible to know, through various pre-conception tests, what chances a mother will have of giving birth to a child with specific disabilities. This is especially true of parents who are carriers of Tay-Sachs disease (a disease which occurs in the descendants of Eastern European Jews and which causes baby to degenerate rapidly, both physically and mentally, becoming blind and usually dying before the age of three). The screening for this disease has been extremely successful in many areas of the country. For example, only one child with Tay-Sachs disease was born in all of California last year.

It is also possible to utilize a process known as amniocentesis as a means of diagnosing a fetus in the uterus. In this process, fluid is drawn from the amniotic cavity by a small needle and syringe. By studying the cells in the fluid, it is possible to determine better than 100 different disabling conditions. However, since it is not economically feasible to test for all conditions, the laboratory technician, genetic counselor and parents-to-be should know what they are looking for. The procedure is most often used in determining whether or not the unborn child has Down's Syndrome.

- *Newborn Screening.* A single drop of blood, taken from each infant shortly after birth and sent to an adequately equipped laboratory, can lead to the immediate prevention of seven terrible retardation-causing diseases: phenylketonuria (PKU), galactosemia, maple syrup urine disease, histidinemia, homocystinuria, tyrosinemia and hypothyroidism. Although a recent Government Accounting Office (GAO) Report on the Prevention of Mental Retardation calls for cost-beneficial, regional, newborn screening centers, only two regions have been organized accordingly. The State Health Department in Portland serves Oregon, Alaska, Montana, Idaho and Nevada; while a similar agency in Boston serves Massachusetts, Maine, Rhode Island, Connecticut and New Hampshire.

If and when such regional newborn screening is accomplished throughout the nation, many children will be rescued from these seven diseases. (Forty-four states do make it mandatory to test for PKU, but they have no laws covering the other six diseases.)

- *Lead Poisoning.* Since the Federal Government's "Lead-Based Paint, Lead poisoning Control Act," we have done a heroic job of stopping the manufacture of paints containing this poisonous metal. However, monitoring paint production amounts to less than half the battle. Better than half of the lead poisoning in this country can be traced to the exhaust pipes of our automobiles. Dr. Robert Guthrie, Professor of Pediatrics and Microbiology, State University of New York at Buffalo gave a vivid description of the problem:

> The Federal Environmental Agency reports that one of the major sources of lead poisoning in the past two decades—affecting small children—comes from the tremendous contamination of soil and dust by the exhaust of tetraethyl lead from our automobiles . . . One health department professional in California, testing the soil downwind from one of the freeways, found that one percent of the dry weight of the top soil was lead. Well, if you have ever watched children play in dirt, and when you know that a child ingesting only a micro-amount of this soil will receive a severe case of lead poisoning, you can't help but become alarmed.

Dr. Guthrie spoke of other significant tests for lead:

> Some interesting tests have been carried out on glacial ice in Greenland. By boring deep into the ice and by carbon dating the ice's formation, it can be shown that lead began appearing around 1940 and its presence has been increasing ever since . . . The presence of lead now appears in the rings of redwood trees. This appearance also coincides with the increase of automobile travel . .
>
> Many tests have shown that the captive dust on the streets of large cities contain an extremely high content of lead.

Such evidence provides us with one more option that is well worth pursing. But will we pursue it? Acting vigorously in our attack on somebody else's manufacture of lead paint is one thing, but attacking the automobiles which are closer to our hearts is something else entirely.

- *The Rubella Problem.* Not so very long ago, rubella—more familiarly known as German Measles—was seen as a mild, three-day illness that simply came and went and afflicted almost everybody. In 1941, however, Norman Gregg of Australia astounded the world when he showed that this seemingly benign illness could be vicious when present in pregnant mothers—especially when it occured during the first trimester. The children of mothers who had rubella were often born with multiple handicaps, including blindness, deafness, heart defects, seizures, cerebral palsy and mental retardation.

At first, many physicians refused to believe that rubella could cause such damage. However, in 1961, proper tools for diagnosing the disease were developed and rubella was recognized for the damage it could do as seen most dramatically in The Epidemic of 1964. In 1966, the first rubella vaccine was administered to children and by 1969, the vaccines were licensed. Since then, more than 80 million doses have been administered—mostly to children because they are the most active carriers of the disease. As a result, this country has not had a rubella epidemic for the past 14 years. (The last major epidemic took place in 1964 and prior to that time, they occured every six to nine years.)

Does this mean we have won over rubella? Definitely not. Dr. Louis Z. Cooper, Professor of Pediatrics, Roosevelt Hospital and Columbia University, New York, explains why:

> Many women are becoming pregnant every day without being aware of their immunity status for rubella and for the few who contract the disease during pregnancy it's just as big a tragedy every time it happens. Many children in the country still haven't received the vaccine, because we have yet to work a thorough and complete immunization program into the nation's service delivery system . . . Regrettably, some people have become complacent and fail to see that the next rubella epidemic is always just around the corner . . . The tragedy of the situation lies in the fact that this disease

> could be stopped dead in its tracks if we could only organize the immunization process into the fabric of our society.

- *The First Two Years of Life* One thing people should understand—although they usually don't—is that the infant, in the first months of life, has a great deal of difficulty throwing off infections carried in the blood. Dr. Cooper explains why this is so:

> When you and I get an infection, it is localized at the point of attack so that only one, two or three organisms can be found in a milliliter of our blood. But when a newborn child gets an infection, he or she may have over a hundred organisms in the same amount of blood. There is still an absence of a number of elements in the blood that can localize and control the infection as it happens in us. Consequently, these organisms may be carried into the bloodstream to the brain. And the brain, being one of the most vulnerable organs in the child, becomes readily susceptible to all kinds of damaging conditions.

This, of course, is one more reason why it makes sense to see that the mother is as healthy as possible before becoming pregnant. She must protect herself from all preventable diseases—not only for her own sake, but for the sake of her child.

- *Rh Problems Can Be Solved* For years, we have known that when a woman with Rh-negative blood and a man with Rh-positive blood conceive a child, they run the risk of having a mentally retarded child. Dr. Koch and his wife, Jean, explain the problem this way:

> Although both parents have normal blood types, the mixture causes trouble. In most cases, the fetus inherits the father's dominant Rh-positive blood. This causes no problems during a first pregnancy because the circulatory systems of mother and baby are separate and their blood usually does not mix. But at delivery, if some of the fetal blood in the placenta inadvertently mixes with the mother's blood, her system will begin forming antibodies to this foreign substance. During her next pregnancy, these antibodies may cross the placenta, enter her baby's circulatory system and systematically destroy the developing red blood cells. This causes the release of bilirubin, one of the pigments in the red blood cells. This substance interferes with the ability of some brain cells to utilize the oxygen carried by the blood. As a result, the affected brain cells are literally starved for oxygen and die. When such a baby is born, its tiny liver cannot cope with the continued destruction of blood cells. As the bilirubin level rises, the infant's skin becomes jaundiced. Such an infant may become mentally retarded or have cerebral palsy or convulsions. Prompt exchange transfusions, in which a newborn is given an entirely new supply of blood, can usually prevent brain damage. A new vaccine, given to the Rh-negative mother immediately after the birth of each child, can keep her system from developing antibodies and ends the possibility of an infant incurring brain damage due to Rh Incompatibility. (*Psychology Today*, December, 1976)

- *Other Facts about Prevention* Americans cannot afford to shrug off mental retardation as something largely beyond their control. Much of it is controllable—through legislation, through common sense and, highly important, through greater knowledge of the problem. With this in mind, consider the following:

Some countries and Canadian Provinces have laws requiring adults to wear safety restraints in automobiles. But few show equal concern for children. However, Tennessee has a law making safety restraints mandatory for children. Infants are highly vulnerable to brain damage as a result of automobile accidents, since the disproportionate weight of their heads tends to turn them into flying missiles within cars making abrupt stops.

Motorcyclists are often vehement in their protests against laws requiring them to wear crash helmets. They believe such laws are an infringement of their right to freedom. Yet for every motorcyclist killed, several others are seriously brain damaged. Much of their care is at government expense.

As noted by Dr. Richard Koch and Jean Koch (in *Psychology Today*, December 1976), every American who is so retarded that he cannot work will cost society $650,000—the money he might have earned during his lifetime.

Hydrocephalus, a condition in which fluid is trapped in the skull, eventually filling the space the brain should occupy, can be corrected by an operation. Unless treated, these babies either suffer early deaths or have severe mental retardation, develop enormous skulls and are generally confined to an institutional bed throughout their lives.

It would perhaps be an exaggeration to say that we live in a drug-oriented culture; nevertheless, drugs play a highly influential role in the lives of a great many Americans. It is not only the highly publicized drugs like heroin and "angel dust" we must worry about. Just as dangerous (because we know so little about them) are the many drugs in common use in everyday life. Until we know more about what these drugs can do, Americans must tread cautiously in their use of them.

Any competent prevention expert could add more options to this list. However, it is hoped that the ones presented here will provide programmatic and prevention workers with a fresh opportunity to increase their interest in one another and to advocate for one another as never before.

Some New Directions

SOME NEW DIRECTIONS

The following concepts, attitudes and beliefs have been distilled from the "programs that work" described in this report. Many are fresh and untested. Nevertheless, it is possible—if not probable—that some of them will richly influence the delivery of services to mentally retarded citizens and their families for years to come.

Incentives to Families. *More and more, agencies and governments are creating incentives that influence families to keep their mentally retarded children within their own homes. These incentives are replacing the financial and social incentives which for years have motivated parents to send their children away to institutions.*

Emphasis on Early Childhood. The first months and years of life are crucial to the development of mentally retarded persons. This should be recognized by service agencies in charge of developing and delivering programs. Services to infants and very young children should be given top priority.

Coordination of Early Intervention Programs. *Community agencies should join forces to deliver programs to "at risk" and developmentally disabled children during infancy and early childhood. Such coordination can take place with little or no additional funds and staff.*

In-Home Services. As governments and agencies assign home-aid resources (e.g., respite care, crisis assistance, etc.) a higher priority on their list of services, more in-home services will be delivered to families with retarded children than ever before.

Child Abuse. *As some in-home services to families with mentally retarded children are increased, the incidence of child abuse will decrease.*

Parent Participation Options. Parents have a wide range of talents and temperaments. The best way to utilize parents is to recognize these differences and provide them with options which they can choose on the basis of their individuality. The worst: to involve them in narrow, heavily structured activities which do not fit their best capabilities.

Assistance for Siblings. *Programs should be designed to help siblings understand and adjust to their retarded brothers or sisters. Here, too, many options should be provided.*

Programs for Low Income Families. Services to low income families are most effective if they take into account the cultural heritage, the dignity and the foreign language problems of minority groups.

Parent-to-Parent Peer Relationships. *Peer group education between parents of mentally retarded children is a powerful force for good. There is a need for more innovative programs based on this principle.*

Consumer Advocacy Systems. Families of retarded citizens should continue to be the creative force behind new and different consumer advocacy thrusts. They should also continue to serve as a balance of power with service agencies so that they can question administrative procedures, make suggestions, reinforce helpful services and expose inefficiency.

Public School Education. *The regular, public school building is the proper setting for school-age, mentally retarded students—except for those students whose medical problems rule out such a possibility.*

Early Childhood Education. Inasmuch as the first months and years of life are critical to human development, public school education of every mentally retarded child should begin at birth.

Special and Regular Student Relationships. *Peer group relationships between special and regular students are extremely valuable to all concerned. Such relationships should be carefully planned, encouraged and used extensively.*

Family-Teacher Relationships. The wide gap which presently exists between families and teachers will narrow as teachers and parents work together in planning the program direction of retarded students. Here, too, the personalities and options of parents and siblings should be recognized and options for involvement provided for.

Regular-Special Teacher Relationships. *As a result of Public Law 94-142, interactions between regular classroom and special education teachers are already taking place. These interactions should be developed even further, for the benefit of all children.*

Community Referenced Education. Classroom education alone does not prepare the mentally retarded person to live with optimum skill in the community. Also needed in addition to classroom activities are well-sequenced, in-the-community assignments.

Professional Preparation. *Colleges and universities should increase the number of hours of competency-based, in-the-field education with mentally retarded students. At the same time, professors of special education should continuously demonstrate and upgrade their own competencies in teaching mentally retarded children.*

Some New Directions

Discrimination in Public Schools. All mandates concerning racial discrimination—beginning with the U.S. Supreme Court's decision in Brown v. Board of Education (1954)—must now apply to mentally retarded students as well.

Special Educators and the Medical Profession. *Competent special educators should become actively involved with medical personnel at the birth of a mentally retarded child or at the earliest moment an infant is identified as such.*

Classes on College and University Campuses. Well-planned adult education programs for mentally retarded persons in such settings will enhance the quality of living for handicapped students and revitalize the education of regular students as well.

Community Attitudes. *Further thought should be given to the problem of community attitudes. The fact that most community residences for retarded persons are located in "transitional" sections of cities indicates that attitudes towards such handicapped citizens may not be as positive as some workers in the field tend to believe.*

Tourism and Residential Programs. The more a residential program blends into a neighborhood, the more awkward tours of such services will become—for the resident and for the touring parties as well.

Local Responsibilities. *For years, communities have tended to pass off the responsibilities for the residential care of retarded citizens to the state or federal government. Now, when some local governments rise to the point of wanting "to care for their own," state and federal red tape can stand in the way.*

Support the Home First. Residential service agencies should do everything possible to help mentally retarded persons live successfully in their own homes before offering other community residence options.

Security for Parents. *In the past, when parents placed their child in an institution, the government informally guaranteed that the child would be cared for after they died. Similar guarantees should be made for parents placing their child in a community residence.*

Careful Community Placements. Residential service experts have learned that the successful movement of retarded adults into the community involves more than just placing them in suitable quarters. They must be carefully taught to live there.

Community Residences in Small Towns. *It is no longer a foregone conclusion that mentally retarded citizens from rural areas and small towns will be better off living in big city facilities.*

Work and Self Esteem. Since the "second question" in most getting-acquainted conversations is "What do you do?", many service delivery agencies should intend to help clients develop such meaningful vocations that they'll be able to answer that second question with pride.

Community Redevelopment Efforts. *Many retarded persons who are incapable of competitive employment could be tremendous forces in public works projects, according to a new breed of vocational training experts, if we organize them effectively and value them for the contributions they can make.*

Training Assignments. Some vocational trainers are convinced that mentally retarded persons learn best in real on-the-job assignments, rather than in isolated, artificial training efforts.

Self-Advocacy Movements. *As mentally retarded clients develop to the point where they can speak for themselves and represent their own interests, service delivery workers must learn to "step back" and become less controlling of their clients' destinies.*

The "Mentally Retarded" Label. There are a growing number of handicapped persons who deeply resent being called "mentally retarded." Workers in the field should become aware of this sensitivity in their clients.

Artistic Talents. *Sometimes, a mentally retarded person may possess considerable artistic talents, even though he or she is unable to read and write. These talents should be encouraged.*

The Mentally Retarded Offender. In many sections of the nation, programs serving mentally retarded persons in trouble with the law quickly collapse when funding crises arise. Programs serving these citzens should be made more substantial and durable.

Retarded Persons with Mental Illness. *Citizens who suffer both retardation and mental illness have not always received the services they need because of differences of economy and technology between the fields of mental illness and mental retardation. The time has come to solve these differences.*

Prevention. If the American people could marshall all that is presently known about preventing mental retardation—biomedically and environmentally—and if all available options were organized and carried out, the incidence of mental retardation would be reduced by one-half.

Metropolitan State College President James Palmer presenting Certificates of Achievement to College for Living students at end-of-term ceremonies.

Scenes from the Musical, 'FATSO.' See page 56.